Adam, Emily, Sleeman, Katherine E, Brearley, Sarah, Hunt, Katherine and Tuffrey-Wijne, Irene (2020) The palliative care needs of adults with intellectual disabilities and their access to palliative care services : a systematic review. Palliative Medicine, 34(8), pp. 1006-1018.
DOI: 10.1177/0269216320932774

*Accepted for publication in **Palliative Medicine** on 18/05/2020*

The palliative care needs of adults with intellectual disabilities and their access to palliative care services: A systematic review

Authors
Emily Adam[1], Katherine E Sleeman[2], Sarah Brearley[3], Katherine Hunt[4], Irene Tuffrey-Wijne[5]

1. Cicely Saunders Institute of Palliative Care and Rehabilitation, King's College London emily.adam1@nhs.net
2. Cicely Saunders Institute of Palliative Care and Rehabilitation, King's College London
3. Lancaster University, Faculty of Health and Medicine
4. University of Southampton, Faculty of Health Sciences
5. Faculty of Health, Social Care & Education, Kingston University & St George's University of London

Abstract

Background: There is evidence that people with intellectual disabilities experience healthcare inequalities, including access to specialist palliative care, but to date there has not been a systematic review of empirical evidence.
Aim: To identify the palliative care needs of adults with intellectual disabilities and the barriers and facilitators they face in accessing palliative care.
Design: Systematic review using a narrative synthesis approach (PROSPERO registration number: CRD42019138974).
Data sources: Five databases were searched in June 2019 (MEDLINE, Embase, PsycINFO, the Cochrane library and CINAHL) along with hand searches and a search of the grey literature. All study designs were included.
Results: 52 Studies were identified, all of which were conducted in high income countries, the majority in the UK (n=28). From a total of 2970 participants across all studies, only 1% were people with intellectual disabilities and 1.3% family members; the majority (97%) were health/social care professionals. Identified needs included physical needs, psychosocial and spiritual needs, and information and communication needs. Barriers and facilitators were associated with education (e.g. staff knowledge, training and experience); communication (e.g. staff skill in assessing and addressing needs of people with communication difficulties); collaboration (e.g. importance of sustained multidisciplinary approach) and health and social care delivery (e.g. staffing levels, funding and management support).
Conclusions: This review highlights the specific problems in providing equitable palliative care for adults with intellectual disabilities, but there is a lack of research into strategies to

improve practice. This should be prioritised, using methods that include people with intellectual disabilities and families.

Keywords: Palliative Care, Health Services Needs and Demand, Intellectual Disability, Health Services Accessibility.

Key statements

What is already known about this topic?

- Adults with intellectual disabilities experience health care inequalities and are less likely to have access to palliative care.
- The specific palliative care needs of people with intellectual disabilities are poorly understood.
- Guidance and policy in this field is mostly built upon theoretical and anecdotal evidence with a very limited empirical knowledge base.

What this paper adds

- While the palliative care needs of adults with intellectual disabilities mirror those of the general population, there are specific and complex challenges associated with these individuals.
- Adults with intellectual disabilities face multiple barriers to accessing palliative care.
- There is a paucity of high quality research in this field and people with intellectual disabilities themselves, and their families, are not represented through the currently available evidence.

Implications for practice, theory or policy

- Addressing the inequalities in accessing palliative care for people with intellectual disabilities should be an urgent international priority.
- Examples of good practice and promising initiatives identified in this review need to be supported by good quality research, embedded in national policy and adequately funded.
- Future research should focus on developing measurable outcomes specifically related to people with intellectual disabilities to allow for large scale interventional studies that demonstrate these initiatives are effective and worthwhile.

Introduction

The global prevalence of intellectual disability is estimated at approximately 1%[1]. Improved health and social care means this population is expanding[1]. While there are various definitions of intellectual disability, there is international consensus that it is present when the following three criteria are met: a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence); a reduced ability to cope independently (impaired social functioning); and beginning before adulthood, with a lasting effect on development[2-4]. In the UK, people with intellectual disabilities make up around 1.5 million people, and this is expected to rise by 1.1% annually, with those aged over 60 years set to increase substantially[5]. With an ageing population comes a rising prevalence of chronic and age-related illness, and subsequently an increased need for palliative and end of life care[5-8].

Despite this trend, people with intellectual disabilities die approximately 25 years sooner than the general population[9]. Evidence from the World Health Organisation (WHO) atlas of global resources for people with intellectual disabilities reveals that people with intellectual disabilities are often denied their right to health care, even in countries with a relatively high standard of living[10, 11]. Worldwide, there is a paucity of documentation, information or epidemiological data about this population[10]. As such it is challenging to fully appreciate the prevalence and impact of intellectual disabilities on health care needs, and the associated barriers and facilitators experienced. Investigations into the deaths of people with learning disabilities in the UK[9, 12, 13] have identified institutional discrimination and considerable evidence of health care inequalities contributing to avoidable excess mortality. In addition, people with intellectual disabilities were less likely to have access to specialist palliative care services and received less opioid analgesia in their final illness than people without intellectual disabilities[13]. The independent regulator of health and social care in England (the Care Quality Commission: CQC) found that exclusion of people with intellectual disabilities from wider health services was a significant barrier to care at end of life[14].

Existing guidance to improve palliative and end of life care for people with learning disabilities is mostly based on theoretical or anecdotal evidence, expert opinion and case reports[6, 14, 15]. Guidance from the National Institute for Health and Care Excellence (NICE) in the UK regarding older people with intellectual disabilities[16] was based on a systematic review which identified only two studies reflecting the views of people with intellectual disabilities and their families. In order to understand more about this gap in knowledge, and about the best direction for further research in this area, it is essential to examine in detail what is known about the inequalities faced by this population. The aim of this systematic review was to identify the palliative care needs of adults with intellectual disabilities and the barriers and facilitators this population face in accessing palliative care

Methods

The protocol for this systematic review was registered in the PROSPERO database[17] (CRD42019138974) and is reported according to the PRISMA guidelines[18].

Review questions

What are the palliative care needs of adults with intellectual disabilities?
What are the barriers and facilitators this population face in accessing palliative care?

Search Strategy

MEDLINE, Embase, PsycINFO, the Cochrane library and CINAHL were searched in June 2019. MeSH terms and key words, guided by previously published systematic reviews[19-21], were combined with a pre-defined palliative care filter[22] to form the search strategy (Appendix 1). Hand searching included two intellectual disability specific journals: The Journal of Applied Research in Intellectual Disabilities (JARID) and The Journal of Intellectual Disability Research (JIDR). These were considered to be the most relevant journals in the field if intellectual disability. They were searched online, without any date restrictions, to check for articles that may not have been captured in the database search. Reference lists of key publications[6, 9, 13-15, 23, 24] and of identified studies were also reviewed. The grey literature was searched online using OpenGrey[25] and CareSearch[26].

Inclusion and exclusion criteria

An inclusive approach was adopted given the paucity of research in this field. Multiple study designs and all health care settings were included and no geographical or date limitations applied. Table 1 details inclusion and exclusion criteria.

Table 1: Eligibility criteria

Inclusion criteria	
Population	• Studies including adult participants aged 18 and over with intellectual disabilities and a 'life-threatening illness' as per the WHO definition of palliative care[27]. • Studies including participants who are carers/relatives or health/social care staff caring for this population.
Setting	• Home, hospital, hospice, nursing/residential home, outpatient, primary care/community. • Worldwide.

Outcomes	• Any outcomes relating to palliative care needs of adults with intellectual disabilities. • Any outcomes describing barriers and/or facilitators to accessing generalist or specialist palliative care.
Study designs	• Qualitative and quantitative research methods. • Experimental study designs: randomised controlled trials (RCTs), quasi-experimental. • Observational study designs: cross-sectional, cohort, case-control. • Prospective and retrospective designs. • Literature reviews and systematic reviews. • Case series and case reports.
Exclusion criteria	
• Discussion and opinion papers, conference abstracts, editorials, letters, comments, guidelines. • Non-English articles where translation cannot be achieved.	

Study Selection

The electronic searches identified 6632 articles. Following removal of duplicates, titles and abstracts were reviewed to assess if they merited full text analysis. A second researcher (ITW) reviewed a sub-set of 100 randomly selected titles and abstracts to check for inter-rater agreement with the primary researcher (EA). Any disagreement was resolved with a third researcher (KES). A kappa value of 0.67[28, 29] demonstrated 'substantial' agreement. Analysis of the full text was then undertaken by EA. Endnote[30] and Rayyan[31] were used to manage the selection process. A total of 52 articles were included for final analysis. Figure 1 details the selection process.

Data extraction

Data were extracted using a Microsoft Excel[32] template (Appendix 2) developed with guidance from the Cochrane 'Checklist of items to consider in data collection or data extraction'[33].

Grading of quality

In order to evaluate the quality of the evidence included in the review, the articles were assessed using Hawker et al's critical appraisal tool (Appendix 3)[34]. This was designed specifically to assess research conducted using different paradigms[34]. It consists of 9 questions, each of which are scored on a four-point scale from very poor (1 point) to good (4 points). Based on a scoring system adapted by Voss et al[20], total scores of 18 or less were defined as poor, 19-27 as moderate and above 27 as good (Appendix 4).

Data analysis

Information was collected for any outcomes relating to the palliative care needs of adults with intellectual disabilities and/or facilitators and/or barriers to accessing palliative care. Due to the heterogeneity of the studies, narrative methods were employed to synthesise the data. This encompassed the generation of themes, which was supported by the qualitative data analysis software NVivo[35]. This narrative synthesis approach involved collating study findings into a textual narrative, along with tables and graphs. It was considered an appropriate choice of method, being suited to both quantitative and qualitative data and where statistical synthesis is not possible[36, 37].

Figure 1: Screening process based on the PRISMA flow diagram[18]

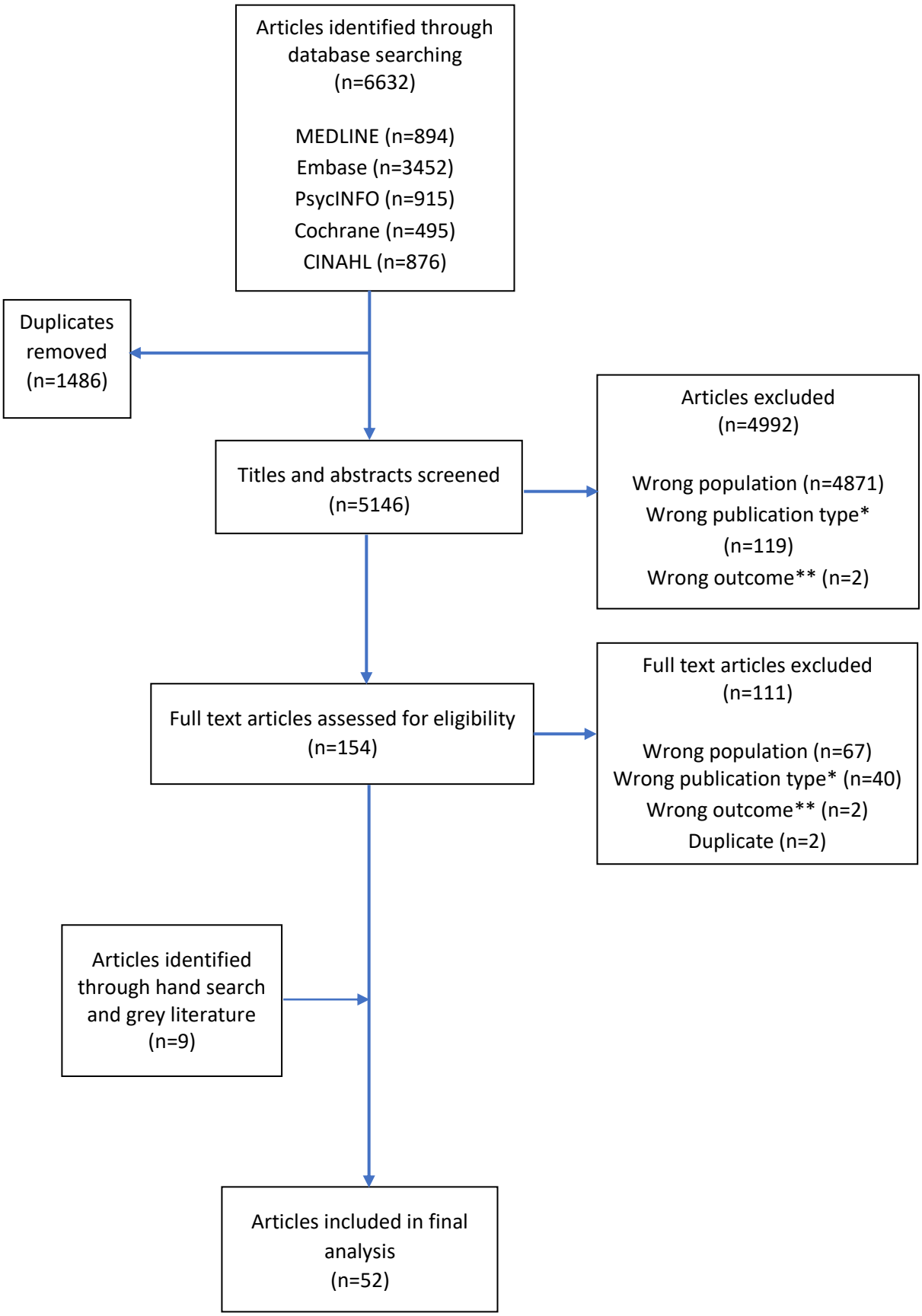


Figure 1 legend

*Wrong publication: fell into one of the following categories in the exclusion criteria: 'discussion and opinion papers, conference abstracts, editorials, letters, comments, guidelines.'

**Wrong outcome: did not include 'Any outcomes relating to palliative care needs of adults with intellectual disabilities' or 'Any outcomes describing barriers and/or facilitators to accessing generalist or specialist palliative care' as listed in the inclusion criteria.

Results

Study Characteristics

All studies were conducted in high income countries, with more than 50% conducted in the UK (Table 2).

Table 2: Geographical location of research

Country	Number of articles
UK	28
Netherlands	6
USA	6
Ireland	4
Australia	3
Multiple European countries	3
Canada	1
New Zealand	1
Total	52

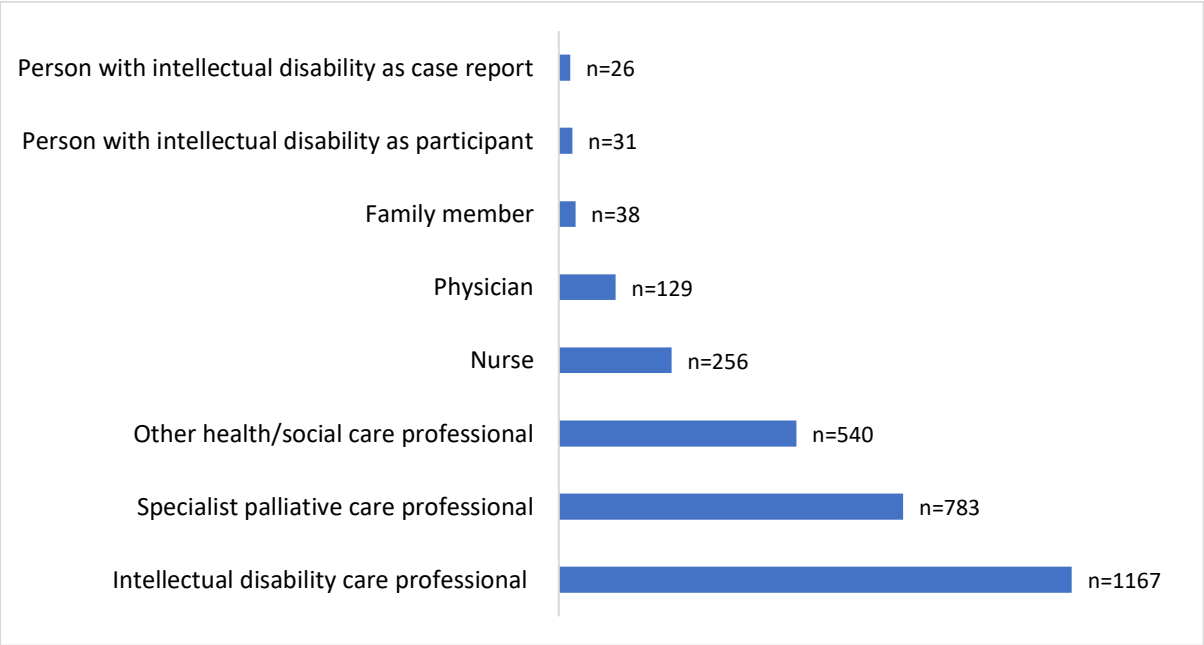
Qualitative methods were the most commonly used (n=17). There were 12 mixed method studies, 12 literature reviews, 10 studies with quantitative methods and 1 systematic review. There were no randomised controlled trials (RCTs). According to Hawker et al's checklist[34], four articles were graded 'poor', 25 were 'moderate' and 23 were 'good' (Appendix 4).

The studies covered a range of health and social care settings including home, hospice, hospital, community, residential and nursing homes. Many studies did not describe the

setting (n=24). For those that did (n=28), most involved participants based in community or residential settings (n=16).

There were 2970 participants included across the 52 studies. The majority of participants were health or social care professionals (n=2875, 96.8%). There were more intellectual disability professionals (n=1167, 39.3%) than there were specialist palliative care professionals (n=783, 26.4%) and more nurses (n=256, 8.6%) than physicians (n=129, 4.3%). There were 38 family members (1.3%) and 31 people with intellectual disabilities and a life-threatening illness (1%) acting as participants themselves (Figure 2).

Figure 2: Participants across studies



Qualitative synthesis

The data were synthesised according to needs, barriers and facilitators.

Needs

Information relating to the palliative care needs of people with intellectual disabilities was identified in 32 studies. With the exception of one paper[38], all of these studies reflected the perspectives of health care professionals or relatives. Three themes were identified: 1) Physical needs, 2) Psychosocial and spiritual needs, 3) Information and communication needs

1) Physical needs

The most common physical need identified by staff was pain management. Many health care professionals described the challenge of symptoms being expressed as objectively observable signs or behaviours such as irritability, inactivity, loss of appetite and sleep disturbance, rather than spontaneous complaints[39]. Other symptoms requiring attention included; nausea, vomiting, fatigue[40], shortness of breath, constipation, delirium[41], urinary incontinence and oral thrush[42]. Monitoring of hydration and nutrition was also important[42-46]. Many patients experienced declining mobility and needed physiotherapy[42, 46, 47]. Physical needs also involved wound care[41, 48], pressure area care[44] and personal care such as washing[49].

2) Psychosocial and spiritual needs

The importance of family and the need for a social network was expressed widely[47, 50, 51]. A study involving interviews with health professionals and carers highlighted that people with intellectual disabilities at the end of life need to be surrounded by people that know them well and can advocate for them[46]. Socialising[52], friendships[3] and human contact[53] are important. People with intellectual disabilities who are dying require continuation of safe routines, treasured activities and important relationships[38]. One study also highlighted the need to be occupied[51]. Many studies recognised the importance of creating a familiar and predictable environment [54]. For many this involved provision of care in the person's home for as long as possible[42, 44, 46, 55]. A change in environment or unfamiliar faces may cause distress and hinder communication[1, 42, 49].

People with intellectual disabilities and a life-limiting illness experience fear and anxiety[38, 49] particularly when receiving bad news[40] or having difficulty understanding medical information[38]. Some studies spoke of grief and loss[45], non-verbal expression of grief[56] and the recognition of complicated grief[3, 56], and endorsed the need for appropriately tailored counselling services[3]. There is also evidence that many people with intellectual disabilities have additional mental health problems which require increased support measures[49]. Spiritual needs were identified, but not explored in detail[46, 47, 52]. The need for culturally appropriate care was also highlighted[45, 46, 48].

3) Information and communication needs

People with intellectual disabilities are often not provided with information in an accessible format[50, 57]. This is important in enabling them to understand their diagnosis, prognosis and the symptomatic course of their illness[1, 58]. It is the responsibility of health care professionals to consider communication differences and the difficulty people with intellectual disabilities may have in understanding abstract concepts[54]. People with intellectual disabilities often need help to express their views and participate in decision making[59]. They need honest communication and opportunities to make choices[46, 60, 61]. This

is also important for advance care planning, with several papers placing emphasis on the need to discuss, document and respect preferred place of care and death, which tended to be home[1, 43, 46, 62, 63].

Barriers and facilitators

Many factors acted as barriers as well as facilitators to providing palliative care to people with intellectual disabilities, depending on whether they were present or absent. Four themes were identified: 1) Education, 2) Communication, 3) Collaboration, 4) Health and social care delivery. A conceptual model of barriers and facilitators was developed from these themes (Figure 3).

1) Education

Education – barriers

Inadequate education was the most widely reported barrier. Particularly evident was the lack of experience, preparation and training in delivering end of life care amongst staff looking after people with intellectual disabilities in community or residential settings[46, 48, 50, 62, 64-70]. Lack of preparedness for seeing residents entering the dying phase of their lives hindered engagement with palliative care services[68]. A survey exploring the educational needs of intellectual disability care practitioners revealed poor understanding of diagnosis and causation of death, which raised concerns about their ability to recognise a dying patient[48]. These issues are compounded by carers working in isolated community settings without access to guidelines[42]. It was often standard practice for support workers to be on their own with residents when they were dying[68] and staff that spent the most time with patients were often the least trained[54].

The data also reflected a need for specialist palliative care professionals to improve their knowledge and experience in managing patients with intellectual disabilities[8, 49, 53, 54, 65, 71-73]. Additionally, several studies highlighted the need to educate registered nurses in both hospital and community settings in caring for patients with intellectual disabilities at the end of life[8, 44, 61, 74-76].

Inadequate training can heighten communication fears[67], lead to lack of confidence amongst staff[51] and elevated levels of stress[45]. An intellectual disability support worker commented in a focus group discussion that there was a tendency of staff in hospital settings to put patients with intellectual disabilities and palliative care needs into the "too-hard basket"[8].

Contributing to this knowledge gap is the absence of formal protocols, policies and guidelines regarding end of life care for people with intellectual disabilities[45, 55, 62]. A study examining guidelines in 11 European countries suggested that European national palliative care guidelines do not meet the needs of people with intellectual disabilities[77]. Lack of organisational policy leads to inconsistent practice across settings and a postcode lottery whereby end of life care outcomes are often determined by individual staff[62, 68, 78].

Education – facilitators

Proposed educational incentives included a hospice resource folder containing information on local intellectual disability services, an intellectual disability toolkit designed to support hospital professionals and recruitment of a hospice intellectual disability link nurse to encourage integrated learning[79]. Some studies suggest specific areas to focus on such as breaking bad news training for staff in intellectual disability settings[40], advanced training on recognition of non-verbal signs of pain[72] and leadership skills[62]. There is evidence that education in the form of a study day for paid carers can lead to improved knowledge and increased awareness about end of life care[67]. A multi-layered approach to learning, delivered at both the individual and organisational level, contributed to successful implementation of the 'Steps to Success Palliative Care Programme' for people with intellectual disabilities living in residential care homes[59].

Professionals working within intellectual disability and palliative care services expressed a desire to learn from each other through joint education, exchange placements and liaison working[71]. Small group discussion between peers[70] and hearing the perspectives of people with intellectual disabilities themselves were also effective educational techniques[70]. Wider approaches are the inclusion of palliative care for people with intellectual disabilities as a core component in medical and nursing curriculums[48] and examinations[1].

2) Communication

Communication – barriers

Many studies reported inadequate communication skills amongst staff working with people with intellectual disabilities[44, 51, 53, 55, 67, 69, 79, 80]. Fear of initiating conversations about death and lack of experience in breaking bad news were widely reported issues[61, 67, 70], with a tendency in intellectual disability settings to keep things positive[70]. Staff were also concerned that they may cause distress to the person with intellectual disabilities[70]. Health care professionals may use complex language[47] and fail to recognise the difficulty people with intellectual disabilities can have in understanding abstract concepts relating to death[56, 57]. An assumption that the person with intellectual disabilities lacks capacity and cannot provide informed consent[58] leads to an over-reliance on carers or relatives as communication proxies[51, 56, 73], facilitates information gatekeeping and prevents open

discussion[38, 51, 73, 79]. This paternalistic approach presents a barrier to effective palliative care[46, 49, 51, 61].

Communication barriers also relate to the impaired ability of a person with intellectual disabilities to express themselves and understand information[51, 53, 55, 69, 80]. People with intellectual disabilities who are non-verbal present a particular challenge for staff and carers[55, 60, 74, 79, 81]. Symptom assessment is difficult, and there may be a diversity in signals that lead to recognition of the dying phase[82]. Acquiescence also presents a challenge for health care professionals, who may not recognise that people with intellectual disabilities are unlikely to question treatment decisions[38]. Difficulties confirming understanding, ascertaining information requirements and establishing wishes[45] can result in failure to involve people with intellectual disabilities in the decision making process[1, 51, 81]. This can lead to conflict and uncertainty when the person's health deteriorates[83]. A UK survey describing end of life care outcomes for adults with intellectual disabilities found that few individuals had their end of life preferences recorded and the majority were not aware they were going to die[63].

Communication – facilitators

A person-centred approach incorporating compassion and empathy are important when caring for people with intellectual disabilities who have difficulty communicating[7, 67, 69]. Taking time to build relationships, gain trust and confirm understanding can facilitate effective communication[1, 43, 49, 51, 60, 73]. As people with intellectual disabilities are likely to take longer to express themselves and may rely on communication tools, health care professionals should allocate more time for consultations[39, 60]. This is particularly important when talking about death and dying[61]. Continuity of care[43, 45, 73] and involvement of a family member can also aid communication[3, 39, 41, 56, 58]. Helping people with intellectual disabilities to understand and cope with bad news requires building of knowledge gradually over time and support from the person's family and professional network[57]. Translating medical terminology into simpler concepts maximises involvement in decision making[43]. Involving speech and language therapists is another approach[46, 55]. Pictorial books designed to help people with intellectual disabilities understand and discuss terminal illness can be helpful[56, 60]. Structured models for breaking bad news to people with intellectual disabilities have also been developed[56, 57].

Tools to aid assessment of physical symptoms include the 'DisDAT' (Distress Assessment Tool)[39, 56, 58, 67], developed for people with severe communication problems including those with intellectual disabilities, the 'REPOS' (Rotterdam Elderly Pain Observation Scale)[41] and the Abbey scale[56]. The 'PALLI' (PALliative care: Learning to Identify in people with intellectual disabilities) is a tool for use by proxies[84].

Collaboration - barriers

Lack of collaboration between services was a widely reported barrier. Most often this was between intellectual disability and specialist palliative care services[44, 53, 62, 65, 71, 72]. Evidence suggests poor referral rates for patients with intellectual disabilities to specialist palliative care services[54, 65, 71], with few patients receiving dual hospice and intellectual disability care[72]. There is a deficiency of established relationships between intellectual disability and palliative care services[72] encompassing a poor understanding of each other's role, what the service is providing and how it is run[54, 65]. For example, one paper described an intellectual disability care home manager who did not know how to access the palliative care team[42]. Another issue is the medical versus social model of care[55, 71]. Carers familiar with the social care model may neglect the physical aspects of care for the dying[48]. Interviews with intellectual disability and specialist palliative care professionals revealed mistrust between services or conflict regarding ownership of the patient[71]. Limited sharing of information between services and poor referrals can lead to inadequate knowledge of the patient[42, 44, 61]. A view that patients require specialist intellectual disability services leads to exclusion from general palliative care services[65] and a reluctance of intellectual disability services to acknowledge death can mean patients who are dying often remain hidden[46].

Family members are often expected to make complex ethical decisions[83] and lack of understanding regarding focus of care in advanced illness[44, 56] can lead to limited cooperation with palliative care services[44]. Conflicts between staff and surrogate decision makers have been cited as a common barrier to hospice care[80]. One study identified several nurses who were barred from visiting a client by family members who feared they would disclose a poor prognosis[57].

Collaboration - facilitators

Collaborative working between palliative care services, intellectual disability services and carers was an effective way to deliver care to people with intellectual disabilities[43, 44, 49, 51, 65, 68, 79]. Earlier involvement of palliative care builds familiarity and trust between staff and services[56]. Incentives such as regional meetings, joint working or shadowing in both clinical areas can be effective[71]. A mixed methods study described the UK's first specialist palliative care home for older people with intellectual disabilities, demonstrating positive results for quality of life[7].

Key to effective collaboration is a multidisciplinary approach allowing shared expertise between intellectual disability, specialist palliative care, hospital services, community teams and GPs[40, 46, 52]. Specialist palliative care professionals found that liaising with intellectual disability professionals who knew the patient well was helpful around issues of mental

capacity and consent[49]. Link-workers acting as conduits between palliative care and intellectual disability services are also helpful[52-54, 65]. Working collaboratively with the family should encompass recognition that they know the person best, building trust, sharing information, involving them in decision making and supporting them emotionally[44, 45, 68, 79].

4) Health and social care delivery

Health and social care delivery - barriers

Diagnostic overshadowing is a prevalent issue[8, 38, 49] resulting in late diagnosis of terminal illness[54] and delayed recognition of dying[82]. Compliance with care, examination or prescribed medication may be a challenge among people with intellectual disabilities[54, 61] which can also compromise identification and management of symptoms. Some doctors declined to take on patients with intellectual disabilities at the end of life because they lacked the time to manage their complex medical issues[8]. People with intellectual disabilities often have unpredictable clinical trajectories making it difficult to prognosticate[56] and an ageing intellectual disability population brings changing health care needs and disease profiles[81]. The authors also observed that time constraints[71], inadequate staffing levels[62, 64, 69] and underfunding[8, 46, 78, 80] were barriers to supporting the additional health care needs of people with intellectual disabilities at the end of life.

An ageing intellectual disability population means parent caregivers are increasingly elderly and for people with intellectual disabilities living at home, lack of home care options means they require transfer to long-term facilities when their health deteriorates and their parents can no longer cope[49, 53]. Given the short-term nature of hospices, many people with intellectual disabilities are misplaced in nursing homes for people much older than themselves, which lack the expertise to meet their needs[7, 47]. There are few nursing homes that have this expertise[7, 49]. Intellectual disability staff resistance to provide end of life care at home may also prompt transfer to hospital or a nursing home when their client's health deteriorates[8].

Health and social care delivery - facilitators

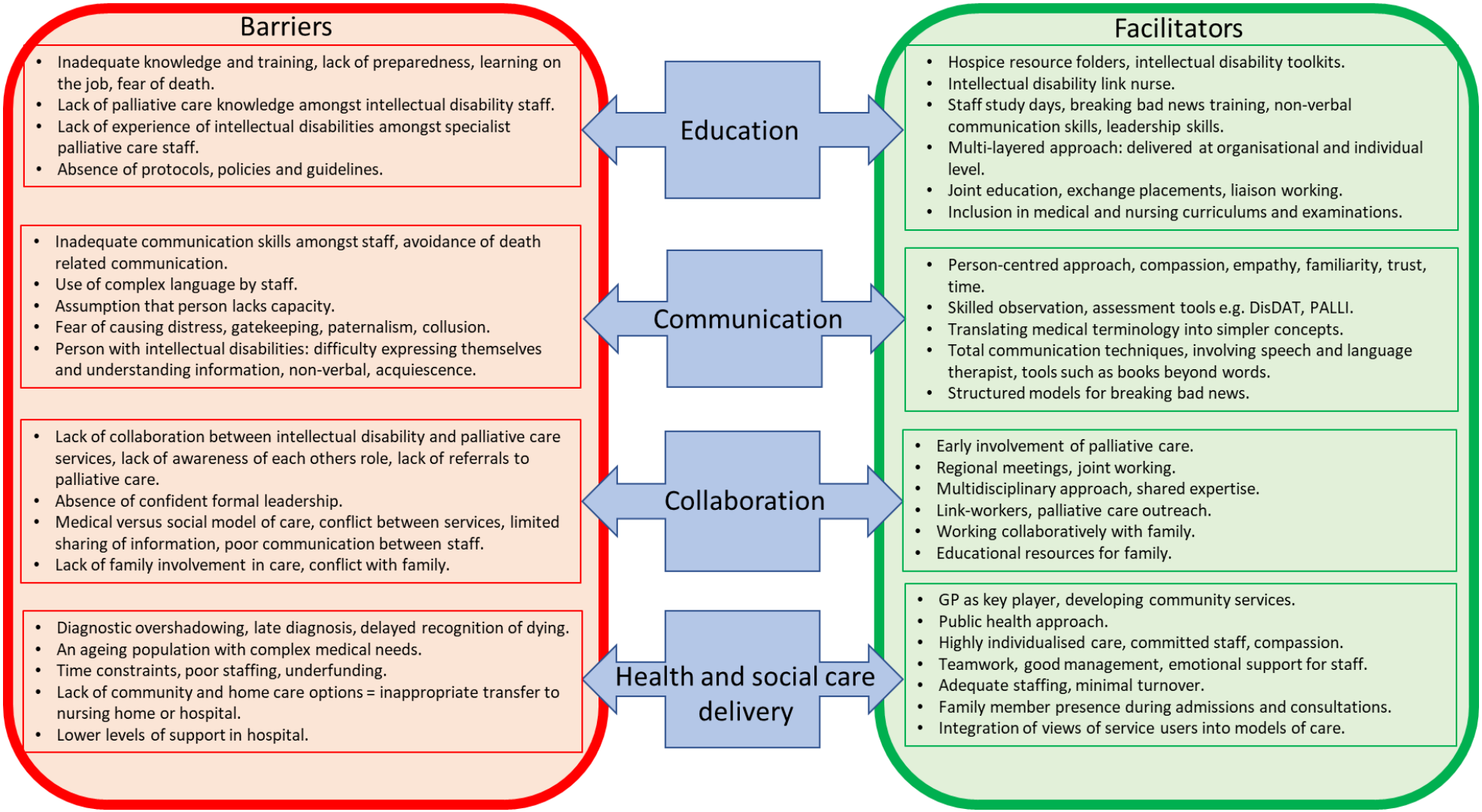
Several studies have highlighted the role of the GP as a key player in identification of need and coordinating referrals for people with intellectual disabilities[43, 46, 71]. Developing community based services with input from GPs and district nurses will support people with intellectual disabilities living at home and allow them to die there[8, 43, 62, 64, 74, 78].

Delivery of palliative care to this population is often dependent on committed staff who are willing to work beyond their call of duty[7, 62, 78]. Delivery of highly individualised care requires teamwork, empathy and enthusiasm[44, 62, 69, 78]. Many studies highlighted the value of good management and support for staff within their own organisation[7, 45, 62, 68]. This should

encompass emotional and bereavement support[38, 46, 61, 67, 68, 71]. Building resilience and empowering the workforce enables them to deal with grief and in turn support the patient[57, 62, 70, 71]. In organisations where managers provided positive role modelling by talking about death and dying, junior staff were more likely to feel comfortable discussing these topics[70]. Adequate staffing and minimal staff turnover were also important to deliver effective and sustainable palliative care to this population[7, 68, 78].

Simple practical adjustments that help people with intellectual disabilities engage with palliative care services include allowing the presence of a family member or keyworker during hospital admissions, consultations and investigations[42, 43, 46] and visits to hospital or treatment units beforehand[40]. Good practice also includes the integration of the views of service users into models of care[45].

Figure 3: Conceptual model of barriers and facilitators to accessing palliative care for adults with intellectual disabilities



Discussion

Main Findings

This systematic review identified 52 studies providing information on the palliative care needs of adults with intellectual disabilities and the barriers and facilitators this population face in accessing palliative care. All of these studies were conducted in high income countries, the majority in the UK. Qualitative methods were most commonly used. The studies mainly reflected experiences from community or residential settings and there was a strong bias towards the experiences of health care professionals. From a total of 2970 participants, just 31 people with intellectual disabilities were included. Identified needs included physical needs, psychosocial and spiritual needs, and information and communication needs. Barriers and facilitators were associated with education, communication, collaboration, and health and social care delivery.

What this study adds

This systematic review provides the first synthesis of the palliative care needs of adults with intellectual disabilities and the barriers and facilitators this population face in accessing palliative care. The current available evidence is almost exclusively reflective of the perspectives of health and social care staff, and the voices of people with intellectual disabilities and their families are lacking.

The palliative care needs identified in this review mirror those of the general population. The European Association for Palliative Care has also made this observation[6]. However, meeting these needs is complicated by the challenges associated with this population. Understanding and recognition of these challenges for each individual, and anticipation of the problems they will face, are key to providing reasonable adjustments, a legal duty of all health and social care services[85] that people with intellectual disabilities so deserve. Addressing education and communication barriers has potential to improve palliative care for this population. Closer attention is needed to how these can be addressed on a wider scale, with accompanying policies and guidelines to standardise practice. This needs to target staff at all levels, across both palliative care and intellectual disability services. Most studies in this review that evaluated interventions were small, and only provided information on the benefits to staff. Large scale interventional studies exploring the effectiveness of interventions in improving palliative care for people with intellectual disabilities are needed. Building links between palliative care and intellectual disability services is crucial. Involving family members and carers is also important in delivering individualised care, as this provides an advocate that knows the person well and can facilitate communication with health care professionals. However, they must act in collaboration with the individual with intellectual disability, involving them in decision making as much as possible, and facilitating their right to autonomy.

The WHO acknowledges the need to improve access to end of life care for hard to reach groups[86]. Indeed, it has been stated that "how we care for the dying is an indicator of how we care for all sick and vulnerable people"[87]. Many of the identified barriers and facilitators to accessing palliative care are likely to be encountered by other socially disadvantaged groups[88, 89]. The conceptual model presented in this paper may therefore be of use to service developers and policy makers in other areas. Thus policy makers have much to learn from acknowledging the barriers faced by this population[79].

Limitations

Only five electronic databases were searched. The hand search included only two intellectual disability specific journals and search of the grey literature was limited to two online databases. However, no date or geographical limitations were applied to the database search, which widened its scope. Although multiple researchers were involved in the screening process, EA conducted data extraction and grading of quality independently, presenting a source of bias. Yet the use of a predefined data extraction template and a structured critical appraisal tool acted to reduce subjectivity as much as possible. It was a challenge judging the quality of such a heterogenous group of studies with one tool, however, Hawker et al's checklist[34] is appropriate to appraise multiple study designs. Loosely defined populations meant in some cases it was difficult to separate participants that were eligible for inclusion alongside those that were not. As far as possible data was only cited where the source of the information was clear, and Figure 2 only includes participants that were clearly defined. The narrative approach used to synthesise the evidence may be seen as subjective and therefore open to bias[36, 37]. However, the use of NVIVO enabled a more systematic approach to this. The data predominantly reflect the experiences of health care professionals in high income countries so may not be generalisable to other settings.

Recommendations for future research

There is a need for high quality studies that not only describe the problems faced by people with intellectual disabilities near the end of life, but evaluate the benefits of specific interventions. The paucity of research in this area further disenfranchises an already marginalised group. Areas to focus on are education, communication and service development. Potential initiatives that could be evaluated in future studies include the effectiveness of toolkits, link nurses, and training days on patient care. Other approaches could be developing assessment tools such as the DisDAT and PALLI. However, this review demonstrates a lack of suitable and validated outcome measures for people with intellectual disabilities and palliative care needs. It is vital that these are developed in order to prove the effectiveness of proposed initiatives in improving care for this population.

Future research must involve people with intellectual disabilities and their family members as active participants. This will provide a deeper understanding of the inequalities experienced by this population and of their priorities and perspectives of what 'good palliative care' looks like. Research should also be encouraged on an international scale, and involve low and middle income countries. This would help in getting palliative care for people with intellectual disabilities on the global health agenda.

Conclusion

Addressing the inequalities in accessing palliative care for people with intellectual disabilities should be an urgent priority, particularly given the ageing population and concomitant co-morbidities. Currently, much of the empirical research in this area has focused on describing the problem. However, there are examples of good practice or pioneering initiatives that have potential to address inequalities in accessing palliative care. Such initiatives need to be evaluated through high quality, appropriately funded research that involves people with intellectual disabilities and their carers, as well as relevant health care professionals. Reliance on "committed individuals"[78] or a "holistic philosophical approach"[7] is not sustainable. Reasonable adjustments should be standard practice and not award-winning exceptions[78]. Good practice in palliative care for this population needs to be standardised and implemented in all health care settings, across specialties and into mainstream services.

Authorship

All authors were involved in the development of the study question. EA registered the study with PROSPERO, performed the literature search, study selection, data extraction, quality assessment, data analysis and wrote the manuscript. ITW and KES participated in study selection. All authors reviewed earlier versions of the manuscript and read and approved the final manuscript.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors. KES is funded by a National Institute for Health Research (NIHR) Clinician Scientist Fellowship (CS-2015-15-005). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR, or the Department of Health.

Declaration of conflicting interests

The Authors declare that there is no conflict of interest.

Ethics

As a systematic review, the study did not directly involve human participants and required no approval from an Ethics Committee or Institutional Review Board.

Data management and sharing

Further information is available at request from the first author.

References

1. Moro TT, Savage TA and Gehlert S. Agency, social and healthcare supports for adults with intellectual disability at the end of life in out-of-home, non-institutional community residences in Western nations: A literature review. *Journal of Applied Research in Intellectual Disabilities* 2017; 30: 1045-1056.
2. Boat and Wu. Mental Disorders and Disabilities Among Low-Income Children. Washington (DC): National Academies Press (US); 2015 Oct 28. Thomas F. Boat and Joel T. Wu. Part II, section 9: Clinical Characteristics of Intellectual Disabilities., https://www.ncbi.nlm.nih.gov/books/NBK332877/ (2015, accessed November 2019).
3. Tuffrey-Wijne I, McLaughlin D, Curfs L, et al. Defining consensus norms for palliative care of people with intellectual disabilities in Europe, using Delphi methods: A White Paper from the European Association of Palliative Care. *Palliative Medicine* 2016; 30: 446-455.
4. WHO. World Helath Organisation (WHO) Regional Office for Europe. Definition: intellectual disability, http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability (2019, accessed May 2019).
5. NEoLCP. The National End of Life Care Programme (NEoLCP): The route to success in end of life care - achieving quality for people with learning disabilities. . (2011).
6. Tuffrey-Wijne I and McLaughlin D. Consensus Norms for Palliative Care of People with Intellectual Disabilities in Europe: EAPC White Paper. Irene Tuffrey-Wijne and Dorry McLaughlin: on behalf of European Association for Palliative Care (EAPC) Taskforce on People with Intellectual Disabilities. (2015).
7. Forrester-Jones R, Beecham JK, Barnoux M, et al. People with intellectual disabilities at the end of their lives: The case for specialist care? *Journal of applied research in intellectual disabilities : JARID* 2017; 30: 1138-1150. DOI: http://dx.doi.org/10.1111/jar.12412.
8. Wark S, Hussain R, Muller A, et al. Challenges in providing end-of-life care for people with intellectual disability: Health services access. *Journal of applied research in intellectual disabilities : JARID* 2017; 30: 1151-1159. DOI: http://dx.doi.org/10.1111/jar.12408.
9. LeDeR. The Learning Disabilities Mortality Review (LeDeR) Programme, University of Bristol Norah Fry Centre for Disability Studies. Annual Report May 2019., http://www.bristol.ac.uk/sps/leder/resources/annual-reports/ (2019, accessed May 2019).
10. WHO. World Health Organization Atlas, Global resources for persons with intellectual disabilities, 2007, https://apps.who.int/iris/bitstream/handle/10665/96353/9789241563505_eng.pdf?sequence=1 (2007, accessed November 2019).
11. Lecomte J and Mercier C. The WHO atlas on global resources for persons with intellectual disabilities: a right to health perspective. *Salud publica de Mexico* 2008; 50 Suppl 2: s160-166. 2008/05/28. DOI: 10.1590/s0036-36342008000800009.

12. Mencap. Death by indifference, Mencap, March 2007. , https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf (2007, accessed November 2019).
13. Heslop P, Blair PS, Fleming P, et al. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet* 2013; 383: 889-895. DOI: 10.1016/S0140-6736(13)62026-7.
14. CQC. Care Qualitly Commission. A different ending: Addressing inequalities in end of life care. Overview report. (2016).
15. PCPLD. Delivering high quality end of life care for people who have a learning disability. Resources and tips for commissioners, service providers and health and social care staff. Developed by NHS England in association with the Palliative Care for People with Learning Disabilities (PCPLD) Network., https://www.england.nhs.uk/publication/delivering-high-quality-end-of-life-care-for-people-who-have-a-learning-disability/ (2017, accessed March 2019).
16. NICE. NICE (National Institute for Health and Care Excellence) guideline [NG96]: Care and support of people growing older with learning disabilities. Published: April 2018., https://www.nice.org.uk/guidance/ng96/evidence (2018, accessed April 2019).
17. PROSPERO. International Prospective Register of Systematic Reviews: PROSPERO. Produced by the Centre for Reviews and Dissemination, University of York, England. Funded by the National Institute for Health Research (NIHR). , https://www.crd.york.ac.uk/prospero/ (2019, accessed May 2019).
18. Moher, Liberati, Tetzlaff, et al. Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement, https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.1000097 (2009, accessed March 2019).
19. Ahmed N, Bestall JE, Ahmedzai SH, et al. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliative Medicine* 2004; 18: 525-542. DOI: 10.1191/0269216304pm921oa.
20. Voss H, Vogel A, Wagemans AMA, et al. Advance Care Planning in Palliative Care for People With Intellectual Disabilities: A Systematic Review. *Journal of Pain and Symptom Management* 2017; 54: 938. DOI: http://dx.doi.org/10.1016/j.jpainsymman.2017.04.016.
21. Wang T, Molassiotis A, Chung BPM, et al. Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. *BMC Palliative Care* 2018; 17: 96. DOI: 10.1186/s12904-018-0346-9.
22. Rietjens JA, Bramer WM, Geijteman EC, et al. Development and validation of search filters to find articles on palliative care in bibliographic databases. *Palliat Med* 2019: 269216318824275. 2019/01/29. DOI: 10.1177/0269216318824275.
23. Observatory. Public Health England Learning Disabilities Observatory: People with learning disabilities in England 2015: Main report. Prepared by: Chris Hatton, Gyles Glover, Eric Emerson and Ian Brown. Public Health England, London. 2016.
24. NHS. The NHS Long Term Plan, January 2019, https://www.longtermplan.nhs.uk/ (2019, accessed April 2019).
25. OpenGrey. OpenGrey: System for Information on Grey Literature in Europe, http://www.opengrey.eu/ (2019, accessed March 2019).
26. CareSearch. CareSearch, https://www.caresearch.com.au/caresearch/tabid/80/Default.aspx (2019, accessed March 2019).
27. WHO. World Health Organisation (WHO) Definition of Palliative Care, https://www.who.int/cancer/palliative/definition/en/ (2019, accessed March 2019).
28. Cohen J. A Coefficient of Agreement for Nominal Scales. *Educational and Psychological Measurement* 1960; 20: 37-46. DOI: 10.1177/001316446002000104.
29. Sim J and Wright CC. The kappa statistic in reliability studies: use, interpretation, and sample size requirements. *Physical therapy* 2005; 85: 257-268. 2005/03/01.

30. Endnote. EndNote, https://endnote.com/ (2019, accessed March 2019).
31. Ouzzani M, Hammady H, Zbys F, et al. Rayyan https://rayyan.qcri.org/welcome (2019, accessed March 2019).
32. Microsoft. Microsoft Excel spreadsheet. 2016.
33. Julian PT Higgins SG. Table 7.3.a: Checklist of items to consider in data collection or data extraction, http://handbook-5-1.cochrane.org/chapter_7/table_7_3_a_checklist_of_items_to_consider_in_data_collection.htm (2011, accessed March 2019).
34. Hawker S, Payne S, Kerr C, et al. Appraising the Evidence: Reviewing Disparate Data Systematically. *Qualitative Health Research* 2002; 12: 1284-1299. DOI: 10.1177/1049732302238251.
35. NVivo. NVivo qualitative data analysis software; QSR International Pty Ltd. Version 12, 2018., https://www.qsrinternational.com/nvivo/what-is-nvivo (2018, accessed September 2019).
36. Snilstveit B, Oliver S and Vojtkova M. Narrative approaches to systematic review and synthesis of evidence for international development policy and practice. *Journal of Development Effectiveness* 2012; 4: 409-429. DOI: 10.1080/19439342.2012.710641.
37. Campbell M, Katikireddi SV, Sowden A, et al. Improving Conduct and Reporting of Narrative Synthesis of Quantitative Data (ICONS-Quant): protocol for a mixed methods study to develop a reporting guideline. *BMJ Open* 2018; 8: e020064. DOI: 10.1136/bmjopen-2017-020064.
38. Tuffrey-Wijne I, Bernal J, Hubert J, et al. People with learning disabilities who have cancer: An ethnographic study. *British Journal of General Practice* 2009; 59: 503-509.
39. Ryan KR and McQuillan R. Palliative care for disadvantaged groups: People with intellectual disabilities. *Progress in Palliative Care* 2005; 13: 70-74.
40. O'Regan P and Drummond E. Cancer information needs of people with intellectual disability: A review of the literature. *European Journal of Oncology Nursing* 2008; 12: 142-147.
41. Vrijmoeth C, Christians MG, Festen DA, et al. Physician-Reported Symptoms and Interventions in People with Intellectual Disabilities Approaching End of Life. *J Palliat Med* 2016; 19: 1142-1147. 2016/09/02. DOI: 10.1089/jpm.2015.0544.
42. Reddall C. A palliative care resource for professional carers of people with learning disabilities. *European Journal of Cancer Care* 2010; 19: 469-475.
43. Marriott A, Marriott J and Heslop P. Good practice in helping people cope with terminal illnesses. *Learning Disability Practice* 2013; 16: 22-25.
44. Bailey M, Doody O and Lyons R. Surveying community nursing support for persons with an intellectual disability and palliative care needs. *British Journal of Learning Disabilities* 2016; 44: 24-34.
45. Welch A and Moreno-Leguizamon C. *Nursing and Palliative Care Literature review of best health and social care practices for individuals with intellectual disabilities encountering the end of life*. 2016, p.118-123.
46. McNamara B, Same A and Rosenwax L. Creating person-centred support for people with intellectual disabilities at the end of life: An Australian qualitative study of unmet needs and strategies. *Journal of Intellectual Disabilities* 2019: 1744629518823887.
47. Flynn S, Hulbert-Williams N, Hulbert-Williams L, et al. Psychosocial experiences of chronic illness in individuals with an intellectual disability: A systematic review of the literature. *Journal of Intellectual Disabilities* 2015; 19: 178-194.
48. Ng J and Li S. A survey exploring the educational needs of care practitioners in learning disability (LD) settings in relation to death, dying and people with learning disabilities. *European Journal of Cancer Care* 2003; 12: 12-19.
49. Tuffrey-Wijne I, McEnhill L, Curfs L, et al. Palliative care provision for people with intellectual disabilities: interviews with specialist palliative care professionals in London. *Palliative Medicine* 2007; 21: 493-499.
50. Tuffrey-Wijne I, Hogg J and Curfs L. End-of-Life and Palliative Care for People with Intellectual Disabilities Who have Cancer or Other Life-Limiting Illness: A Review of the Literature and Available

Resources. *Journal of Applied Research in Intellectual Disabilities* 2007; 20: 331-344. DOI: 10.1111/j.1468-3148.2006.00350.x.
51. Dunkley S and Sales R. The challenges of providing palliative care for people with intellectual disabilities: a literature review. *International Journal of Palliative Nursing* 2014; 20: 279-284.
52. Read S and Cartlidge D. Critical reflections on end-of-life care for people with intellectual disabilities: a single case study approach. *International Journal of Palliative Nursing* 2012; 18: 23-27.
53. Stein GL. Providing palliative care to people with intellectual disabilities: services, staff knowledge, and challenges. *Journal of Palliative Medicine* 2008; 11: 1241-1248.
54. Tuffrey-Wijne I, Whelton R, Curfs L, et al. Palliative care provision for people with intellectual disabilities: a questionnaire survey of specialist palliative care professionals. *Palliative Medicine* 2008; 22: 281-290.
55. Brown H, Burns S and Flynn M. 'Please don't let it happen on my shift!' Supporting staff who are caring for people with learning disabilities who are dying. *Tizard Learning Disability Review* 2003; 8: 32-41.
56. Sue K, Mazzotta P and Grier E. Palliative care for patients with communication and cognitive difficulties. *Canadian Family Physician* 2019; 65: S19-S24.
57. Tuffrey-Wijne I. A new model for breaking bad news to people with intellectual disabilities. *Palliative Medicine* 2013; 27: 5-12. DOI: 10.1177/0269216311433476.
58. Tuffrey-Wijne I. The palliative care needs of people with intellectual disabilities: a literature review. *Palliative Medicine* 2003; 17: 55-62.
59. Kinley J, Denton L and Scott S. Development and implementation of the Steps to Successful Palliative Care programme in residential care homes for people with a learning disability. *International journal of palliative nursing* 2018; 24: 492-502. DOI: http://dx.doi.org/10.12968/ijpn.2018.24.10.492.
60. Tuffrey-Wijne I and McEnhill L. Communication difficulties and intellectual disability in end-of-life care. *International Journal of Palliative Nursing* 2008; 14: 189-194.
61. Morton-Nance S and Schafer T. End of life care for people with a learning disability. *Nursing Standard* 2012; 27: 40-47.
62. Grindrod A and Rumbold B. Providing end-of-life care in disability community living services: An organizational capacity-building model using a public health approach. *Journal of Applied Research in Intellectual Disabilities* 2017; 30: 1125-1137.
63. Hunt K, Bernal J, Worth R, et al. End-of-life care in intellectual disability: a retrospective cross-sectional study. *BMJ Supportive & Palliative Care* 2019: bmjspcare-2019-001985. DOI: 10.1136/bmjspcare-2019-001985.
64. Botsford AL. Status of end of life care in organizations providing services for older people with a developmental disability. *American journal of mental retardation : AJMR* 2004; 109: 421-428. 2004/08/10. DOI: 10.1352/0895-8017(2004)109<421:soeolc>2.0.co;2.
65. Cross H, Cameron M, Marsh S, et al. Practical approaches toward improving end-of-life care for people with intellectual disabilities: effectiveness and sustainability. *Journal of Palliative Medicine* 2012; 15: 322-326.
66. Bekkema N, de Veer A, Hertogh C, et al. Respecting autonomy in the end-of-life care of people with intellectual disabilities: A qualitative multiple-case study. *Journal of Intellectual Disability Research* 2014; 58: 368-380.
67. Codling M, Knowles J and Vevers A. End-of-life training for paid carers working with people with learning disabilities. *British Journal of Community Nursing* 2014; 19: 170, 172-176.
68. O'Sullivan G and Harding R. Transition: the experiences of support workers caring for people with learning disabilities towards the end of life. *BMJ supportive & palliative care* 2017; 7: 158-163. DOI: http://dx.doi.org/10.1136/bmjspcare-2014-000771.
69. Kim J and Gray JA. Palliative Care Experiences and Needs of Direct Care Workers. *Journal of Palliative Medicine* 2018; 21: 1094-1099.

70. Tuffrey-Wijne I, Rose T, Grant R, et al. Communicating about death and dying: Developing training for staff working in services for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 2017; 30: 1099-1110. DOI: 10.1111/jar.12382.
71. McLaughlin D, Barr O, McIlfatrick S, et al. Developing a best practice model for partnership practice between specialist palliative care and intellectual disability services: a mixed methods study. *Palliative Medicine* 2014; 28: 1213-1221.
72. Ronneberg CR, Peters-Beumer L, Marks B, et al. Promoting collaboration between hospice and palliative care providers and adult day services for individuals with intellectual and developmental disabilities. *Omega - Journal of Death & Dying* 2015; 70: 380-403.
73. Ryan K, Guerin S and McEvoy J. The nature and importance of quality of therapeutic relationships in the delivery of palliative care to people with intellectual disabilities. *BMJ supportive & palliative care* 2016; 6: 430-436.
74. Lindop E and Read S. District nurses' needs: palliative care for people with learning disabilities. *International Journal of Palliative Nursing* 2000; 6: 117-122.
75. Bekkema N, de Veer AJ, Albers G, et al. Training needs of nurses and social workers in the end-of-life care for people with intellectual disabilities: a national survey. *Nurse Educ Today* 2014; 34: 494-500. 2013/08/27. DOI: 10.1016/j.nedt.2013.07.018.
76. Northway R, Todd S, Hunt K, et al. Nursing care at end of life: a UK-based survey of the deaths of people living in care settings for people with intellectual disability. *Journal of Research in Nursing* 2019; 24: 366-382. DOI: 10.1177/1744987118780919.
77. Sampson EL, van der Steen JT, Pautex S, et al. European palliative care guidelines: how well do they meet the needs of people with impaired cognition? *BMJ supportive & palliative care* 2015; 5: 301-305.
78. Tuffrey-Wijne I and Davidson J. Excellence in palliative and end-of-life care provision for people with intellectual disability. *International Journal of Palliative Nursing* 2018; 24: 598-610.
79. Cartlidge D and Read S. Exploring the needs of hospice staff supporting people with an intellectual disability: a UK perspective. *Int J Palliat Nurs* 2010; 16: 93-98. 2010/03/12. DOI: 10.12968/ijpn.2010.16.2.46755.
80. Friedman SL, Helm DT and Woodman AC. Unique and universal barriers: hospice care for aging adults with intellectual disability. *American Journal on Intellectual & Developmental Disabilities* 2012; 117: 509-532.
81. McKechnie RC. What does the literature tell us about death, dying and palliative care for people with intellectual disabilities? *Progress in Palliative Care* 2006; 14: 255-259.
82. Vrijmoeth C, Christians MGM, Festen DAM, et al. Physicians' recognition of death in the foreseeable future in patients with intellectual disabilities. *Journal of Intellectual Disability Research* 2016; 60: 207-217.
83. Wagemans AM, Van Schrojenstein Lantman-de Valk HM, Proot IM, et al. End-of-life decisions for people with intellectual disabilities, an interview study with patient representatives. *Palliat Med* 2013; 27: 765-771. 2013/01/09. DOI: 10.1177/0269216312468932.
84. Vrijmoeth C, Echteld MA, Assendelft P, et al. Development and applicability of a tool for identification of people with intellectual disabilities in need of palliative care (PALLI). *Journal of Applied Research in Intellectual Disabilities* 2018; 31: 1122-1132.
85. Public Health England: Guidance: Reasonable adjustments: a legal duty, Published 8 May 2016, https://www.gov.uk/government/publications/reasonable-adjustments-a-legal-duty/reasonable-adjustments-a-legal-duty (2016, accessed May 2020).
86. WHO. World Health Organisation, The solid facts, Palliative Care, Edited by Elizabeth Davies and Irene J Higginson, http://www.euro.who.int/__data/assets/pdf_file/0003/98418/E82931.pdf (2004, accessed February 2020).
87. DOH. Department of Health: End of Life Care Strategy: Promoting high quality care for all adults at the end of life

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf (2008, accessed November 2019).
88. Bonevski B, Randell M, Paul C, et al. Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC Medical Research Methodology* 2014; 14: 42. DOI: 10.1186/1471-2288-14-42.
89. Hawley P. Barriers to Access to Palliative Care. *Palliat Care* 2017; 10: 1178224216688887-1178224216688887. DOI: 10.1177/1178224216688887.

Supplementary data: appendices

Appendix 1	Example of search strategy: MEDLINE
Appendix 2	Data extraction table
Appendix 3	Hawker et al's critical appraisal tool
Appendix 4	Grading of quality

Appendix 1 : Example of search strategy: MEDLINE

Database: Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily <1946 to June 11, 2019>

Search Strategy:

Palliative care:

1 exp Terminal Care/ or caregiver$.mp. or bereave$.mp. or inpatient.tw. or attitude to death.mp. or end of life.af. or hospice$.mp. or terminally ill.mp. or palliative$.mp. or Advance Care.af. or palliat.af. or advanced.af. or (morphine and cancer).af. or cancer pain.af. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] (841709)

Intellectual disability:

2 exp Intellectual Disability/ (92889)

3 exp Learning Disorders/ (21509)

4 (mental* or developmental* or intellectual* or cognitive or learning).ab,ti. (1093120)

5 (retard* or disab* or deficien* or delay*).ab,ti. (1185948)

6 4 and 5 (153599)

7 2 or 3 or 6 (227297)

Needs:

8 exp "Health Services Needs and Demand"/ (57615)

9 exp Needs Assessment/ (28555)

10 (needs assessment or assessment of healthcare needs or assessment of health care needs or unmet needs).ab,ti. (10359)

Access:

11 exp Health Services Accessibility/ (104713)

12 exp Healthcare Disparities/ (14484)

13 (access or access to care or barriers to care or obstacles or equity of care or inequity or inequality or allocation of health care resources or rationing or gate keeping or evaluation of care or quality of health care or assessment of need or unmet need or health care need or pattern of referral or referral).ab,ti. (420591)

Needs OR Access:

14 8 or 9 or 10 or 11 or 12 or 13 (570630)

Palliative care AND Intellectual disability AND [Needs OR Access]:

15 1 and 7 and 14 (894)

****

Appendix 2: Data extraction table

Author/date	Title	Published in	Country	Study design	Aim	Population	Setting	Needs	Facilitators	Barriers
(Bailey et al., 2016)	Surveying community nursing support for persons with an intellectual disability and palliative care needs	British Journal of Learning Disabilities	Ireland	Descriptive cross sectional survey	To describe the provision of community nursing support for persons with an ID and palliative/end-of-life care needs.	Public Health Nurses (PHN), Community Nurses, Practice Nurses, Hospice at Home Nurses and Palliative Care Nurses (n=33)	A health service region in Ireland	Information, advice, emotional support, symptom management, nursing care at home, nutrition management, pressure area care, referral to agency, hospice referral.	Family involvement/ support, nursing experience of ID, teamwork/ collaboration between care providers, support from ID services, personal attributes of professionals: compassion, communication, knowledge, honesty. Building a relationship with patient/ family.	Lack of cooperation from family, lack of experience/ education/ knowledge/ communication skills, lack of co-ordination within/ between services, delay in recognising end of life, delay in referral to PC, lack of ACP, poor referral information, lack of knowledge about patient.
(Bekkema et al., 2014a)	Respecting autonomy in the end-of-life care of people with intellectual disabilities: a qualitative multiple-case study	Journal of Intellectual Disability Research	Netherlands	Qualitative interviews	To describe how caregivers and relatives shape respect for autonomy in the end-of-life care for people with ID.	16 relatives & 31 HCP involved in the care of 12 recently deceased patients with ID	10 ID care provider organisations in different parts of the Netherlands.	Information, autonomy, need to communicate wishes, involvement in decision making, physical care.	Knowledge/skills in end of life care: communication skills, recognising EOL care needs, ability to interpret symptoms. Education.	Lack of HCP experience, knowledge and skills.
(Bekkema et al., 2014b)	Training needs of nurses and social workers in the end-of-life care for people with intellectual disabilities: A national survey	Nurse Education Today	Netherlands	Postal survey	To gain insight into the quality of end-of-life care, past vocational training, training needs and expert consultation opportunities of nurses and social workers working in ID care services.	Nursing staff (n=93), Social workers (n=37).	Working in care services for people with ID in the Netherlands.		Collaborative working between ID and SPC services.	Lack of training/education in EOL care. Lack of access to external experts i.e. SPC.
(Botsford, 2004)	Status of End of Life Care in Organizations Providing Services for Older People with a Developmental Disability	American Journal on Mental Retardation	USA	Survey (paper & electronic questionnaire)	To establish a baseline of information on the current status of end of life care in organizations serving older people with an ID and their families.	160 professionals providing services to older people with an intellectual disability and their families.	National organizations delivering a range of services to people with ID		Training staff, coordinated system of care in the community, availability of resources on EOL care for HCPs/ family/ carers/ patients, policies & guidelines, ACP	Availability of direct care staff, Availability of nursing/ medical staff/ funding, Staff untrained in EOL care, Anxiety about responding to families, Concerns about liability.
(Brown et al., 2003)	'Please don't let it Happen on my Shift!' Supporting Staff who are Caring for People with Learning Disabilities who are Dying	Tizard Learning Disability Review	UK	Qualitative: case series, interviews, observation of team meetings.	Not stated	Case series: 21 people with ID and terminal illness who had died. Interviews: 31 care staff, 16 service managers, 18 health care/ID professionals, 3 service users, 6 family members, 8 local community representatives, 1 external representative. Meetings: 5 staff meetings, 1 group of older people with ID.	12 services that have cared for a person with ID during a terminal illness. Staffed housing (3), residential home (3), hospital (2), community (2), hospice (1), respite service (1).	Pain, care at home, information	Speech and language therapist to aid communication, relationships/knowing the patient,	Diagnostic overshadowing, late diagnosis, difficulty communicating, reluctance to investigate, uncertain trajectory, lack of co-ordination between health & social services, absence of formal protocols, lack of clear legislation (e.g. consent, mental capacity, proxy decision makers), fear of disclosure/ collusion, conflict between carers and family members

(Cartlidge and Read, 2010)	Exploring the needs of hospice staff supporting people with an intellectual disability: a UK perspective	International Journal of Palliative Nursing	England	Qualitative: 2 questionnaires, 1 focus group discussion	To identify what educational and preparation skills hospice staff felt were needed to enable them to feel confident in providing specialist palliative care to people with ID.	Questionnaire: inpatient unit staff (n=26). Focus group discussion: inpatient unit & H@H staff (n=17)	North Staffordshire hospice: 28 beds, day hospice, H@H & education unit.	Management of multi-morbidities	Access to professional expertise, collaborative working alongside ID nurses, ID link nurse, access to resources, ID toolkit, collaborative working with family, staff support	Communication challenges, lack of experience/ knowledge/ skills/ education/ training, difficulty determining patient understanding, collusion, difficult family dynamics, challenging behaviours of patient, uncertainties in managing co-morbidities, stigma.
(Codling et al., 2014)	End-of-life training for paid carers working with people with learning disabilities	British Journal of Community Nursing	England	Focus group discussion & evaluation forms	To implement and evaluate a study day for paid carers on end-of-life care for people with ID.	Paid carers working with individuals with ID (n=43)	Residential care homes, day centres, respite care centres, supported living settings. East & West Berkshire.		Person-centred care/end-of-life plans, Supervision, Assessment tools, Training/guidance about services available and how to access, emotional support for staff	Views of people with learning disability differ from parents, Opportunities to talk about death, Recognising and treating pain, too many professionals /do not understand the roles. Inadequate training heightening communication fears.
(Cross et al., 2012)	Practical Approaches toward Improving End-of-Life Care for People with Intellectual Disabilities: Effectiveness and Sustainability	Journal of Palliative Medicine	England	Staff training sessions. Evaluation: discussions with steering group, face-to-face and telephone interviews.	To capture the learning from a 3 year project aimed at exploring ways of increasing access to palliative care services by people with ID within one geographical area.	ID and palliative care staff	South West London: 4 hospices & 228 care homes		Collaboration between ID and SPC services, PC training for ID staff.	Lack of understanding of each other's role between palliative care professionals and ID staff, tension between specialism and generic working across boundaries, lack of inclusion of people with ID into mainstream services - a view that they require specialist services.
(Dunkley and Sales, 2014)	The challenges of providing palliative care for people with intellectual disabilities: a literature review	International Journal of Palliative Nursing	UK	Literature review	To explore the challenges of providing effective palliative care for people with ID.	Adults with ID & palliative care needs and those caring for them	90 publications from North America, Europe, and the UK.	Communication needs. Time: everything takes longer. Expression of views/ right to information/ involvement in one's own care, having friends and family around, being occupied, physical comfort.	Collaboration between ID and SPC services, early referral of people with ID to SPC, emotional support for staff, training (=confidence/ better communication), knowing the patient, use of assessment tools	Lack of staff confidence and knowledge. Communication: assessment, consent, patient comprehension, collusion, involvement of patients in their end-of-life care/ ACP. Relatives as gatekeepers/ often want to protect. Paternalistic approach of health care. Diagnostic overshadowing.
(Flynn et al., 2015)	Psychosocial experiences of chronic illness in individuals with an intellectual disability: A systematic review of the literature	Journal of Intellectual Disabilities	UK	Systematic review	To identify, evaluate and synthesize literature exploring the psychosocial experiences of chronic illness in adults with ID.	2 pts with ID and life-limiting illness: 30 F with CP &NHL, 44M with CP & advanced penile cancer.	UK, setting not stated.	Spiritual, psychological, physiotherapy, physical effects of surgery-loss of mobility, support from family/friends.		Delayed diagnosis, reluctance to investigate, use of complex language by health care professionals, placed in wards or homes for older people.
(Forrester-Jones et al., 2017)	People with intellectual disabilities at the end of their lives: The case for specialist care?	Journal of Applied Research in Intellectual Disabilities	England	Mixed methods: observations, interviews, questionnaires, costs analysis	To explore the organizational context of a specialist palliative and end-of-life care home to see how it related to the quality of life of people with ID who were approaching the end of their lives.	Residents (n=9), staff members (n=15)	A specialist, high dependency registered nursing home for older people with ID, South England.		Holistic approach: small number of residents allowing more individual staff–client time, provision of activities & therapies in addition to clinical & social care. Person-centred approach: incorporating dignity, knowing people well, compassion/ empathy, especially when communication difficult. Staff making efforts to offer choice & independence. Homely social environment. Emphasis on early admission following terminal diagnosis to avoid transition close to death, recognition of 'unknown time-factor,' long term care until you die - unlike hospice. Supportive	People with ID being "misplaced in older people's homes living alongside much older and more incapacitated people."

									management: responsive to staff needs, willingness to organize training, familiarity with residents. Willingness of staff to go "extra mile" to improve residents' quality of the life. Adequate funding: this service costs!	
(Friedman et al., 2012)	Unique and Universal Barriers: Hospice Care for Aging Adults with Intellectual Disability	American Journal on Intellectual and Developmental Disabilities	USA	Literature review	To better understand the unique barriers to end-of-life care for aging adults with ID.	Adults with ID/end of life care needs and those caring for them	42 articles (US, UK, Belgium, Ireland, Netherlands, New Zealand).	Information needs - considers cultural and communication differences.	Training of care providers	Delay in diagnosis, Late referral to hospice, Reluctance to broach subject, financial constraints, lack of resources, lack of knowledge, carer familiarity with PC, Incomplete communication of treatment options, Conflicts between carers and surrogate decision makers, Ethical dilemmas regarding over/ undertreatment, Challenges with informed consent.
(Gilbert et al., 2007)	Supporting people with intellectual disability in the cancer journey: The 'Living with cancer' communication pack	European Journal of Oncology Nursing	UK	Evaluation: document review, focus groups, postal questionnaire, telephone interview.	An evaluation of the effectiveness of the 'Living with cancer' communication tool.	Focus groups: 6 adults with ID. Questionnaires: 18 ID professionals. Telephone interviews: 7 ID professionals.	ID services across UK.		Use of a tool designed by experts, encompassing 'total communication techniques' to aid communication and discussion of sensitive issues.	
(Grindrod and Rumbold, 2017)	Providing end-of-life care in disability community living services: An organizational capacity building model using a public health approach	Journal of Applied Research in Intellectual Disabilities	Australia	Mixed methods: online survey, focus groups, interviews.	To identify structural, cultural and practical factors that influence end-of-life outcomes for people with ID in the community.	ID professionals in the community: survey (n=179), focus groups (n=25), interviews (n=7)	Community ID services, Victoria, Australia	Asking, recording and respecting preferred place of care and death.	Past experience. Leadership skills. Staff support - emotional & educational. Teamwork/ support from colleagues. Committed staff working additional hours. Clear policies/ protocols. Relationship with patient. Staff resilience. Public health approach.	Staff attitudes: dying best managed by medically trained, not in my job role, death should be in hospital or nursing home. Lack of awareness of policy/ protocol. Lack of training/ experience. Inadequate staffing levels. Patients not offered choice. Absence of coordination between ID staff & SPC. Juggling needs of multiple stakeholders. Staff stress/ feeling unsupported. Fear of impact on other residents: grief/ resources taken up by dying. Absence of confident formal leadership. Inconsistent practice/ policy between settings.
(Hunt et al., 2019)	End-of-life care in intellectual disability: a retrospective cross-sectional study	BMJ Supportive & Palliative Care	UK	Retrospective cross-sectional survey	To describe the end-of-life care outcomes for adults with ID living in residential care in the UK using the VOICES-SF questionnaire and compare these with the general population	157 care staff involved in care of person with ID in last months of life	38 providers of residential care for adults with ID across the four countries of the UK.	Pain	GP and community nurse input. Recording PPD: Of those that did, the majority died in what was reported to be the preferred place.	Patient lack of awareness that they were dying. Preferred place of death not recorded. Lack of involvement in their own care. Hospital based care inferior to community-based care with lower levels of support from external services.

(Kim and Gray, 2018)	Palliative Care Experiences and Needs of Direct Care Workers	Journal of Palliative Medicine	USA	Focus groups	To explore direct care workers experience with PC and their perceived challenges.	Direct care workers serving people with ID (n=54)	5 non-profit community-based organisations providing residential and day services for people with ID in urban and suburban areas within or surrounding a large Midwestern city.		Empathy. Extra attention. Adaptation in care/ taking more time. Peer support/ teamwork.	Difficulties in communication with patient. Anxiety in anticipating death. Limited organisational resources or support; understaffing, inadequate communication between staff of different grades/ specialities, insufficient training.
(Kinley et al., 2018)	Development and implementation of the Steps to Success Palliative Care programme in residential care homes for people with a learning disability in England	International Journal of Palliative Nursing	England	Literature review, meetings with ID, SPC & care home staff.	To develop and implement a palliative care programme that would meet the needs of people with a LD, their families and care home staff.	Care home, ID and SPC staff.	30 care homes		Delivery of an evidenced based formal staff education programme: improved identification/ assessment/ symptom management/ ACP/ changed attitudes towards EOL. Collaboration between services. Learning at an individual, organisational and systems level. Ongoing facilitation/ training new staff to achieve sustainability.	
(Lindop and Read, 2000)	District nurses' needs: palliative care for people with learning disabilities	International Journal of Palliative Nursing	England	Focus groups, questionnaires	Identify national PC issues, and current PC services provided by DNs for people with ID in North Staffordshire, UK.	Focus groups:12 DNs undertaking a diploma in PC. Questionnaires: 106 DNs (54% had contact with ID patients with PC needs).	North Staffordshire, DNs in community	Pain, information, care in the community.	Education and training of district nurses.	Communication difficulties. Lack of experience/ training.
(Marriott et al., 2013)	Good practice in helping clients cope with terminal illness	Learning Disability Practice	England	Case study	To provide an example of good practice in end of life planning and palliative care for a person with ID.	Male in 50s with lung cancer and mild ID	England: hospital & community.	Dietary & nutrition needs. Assistance with complicated medication regime. Pain. Wish to die at home.	Thorough and timely investigation. Allowing enough time for appointments to ensure understanding. Translating medical terminology into simpler concepts to maximise involvement in decisions. Continuity of care with same hospital consultant. Allocation of CLDT nurse. Collaboration between services. Family involvement. Building relationships with patient. Anticipating future needs/ACP, documenting wishes. Regular GP & DN visits. GP as key player.	
(McKechnie, 2006)	What does the literature tell us about death, dying and palliative care for people with intellectual disabilities?	Progress in Palliative Care	New Zealand	Literature review	Not stated.	Not stated.	Not stated.			Difficulties in detecting disease in people who are non-verbal, diagnostic overshadowing, delayed diagnosis. Lack of involvement of the individual in their care: decisions being made for them by family members or health practitioners. Inadequate education of formal and informal carers. Changing healthcare needs/ disease profiles as people with ID are living longer. Health professionals making assumptions about understanding/ ability. Legal barriers around informed consent, capacity and competence.

(McLaughlin et al., 2014)	Developing a best practice model for partnership practice between specialist palliative care and intellectual disability services: A mixed methods study	Palliative Medicine	UK	Questionnaires & interviews	To develop a best practice model which would guide and promote partnership practice between specialist palliative care and ID services	Questionnaires: ID services (n=10), SPC services (n=22), ID nursing homes (n=15). Interviews: 30 HCPs who had provided EOL care to adults with ID.	Primary and secondary care in one region of the UK.		Partnership working between ID and SPC: easy to contact, regional meetings, joint study days, joint working/shadowing in both clinical areas. Co-ordination and continuity of care, familiarity with the patient. Educating, supporting and empowering staff. The role of the GP: early identification of need and specialist referral.	'Medical' versus 'social' model of care, time constraints, limited/ late referrals to SPC, mistrust/ conflict between services.
(McNamara et al., 2019)	Creating person-centred support for people with intellectual disabilities at the end of life: An Australian qualitative study of unmet needs and strategies	Journal of Intellectual Disabilities	Australia	Interviews	Use the perspectives of health professionals and paid carers to document the range of needs adults with an ID experience during the last months of their lives	Nurses (9), social workers (4), occupational therapists (3), disability residential accommodation managers (6), disability support workers (2), psychologists (2)	Community PC organization, community nursing organization, disability accommodation services, public hospital, country health service. Western Australia.	ACP. Enabled to die in familiar surroundings: dying at home. Full time (24/7) care as illness progresses. Pain. Symptom control. Physio & OT needs: repositioning/ wheelchairs. Person-centred care: awareness of social/ethnic background, personal history and modes of communication. Opportunities for choice. Religious/ spiritual needs. Nutrition.	Open communication with the person and their family. Good staff support and bereavement care. Familiarity with patient. Collaboration between MDT. Continuity of HCP. Greater openness/ awareness & strong advocacy. Identify case coordinator/manager, shared care between services, training ID staff in PC/training PC staff in ID, available PC guides/policies, routine use of disability-oriented pain/symptom assessment tools, early identification & referral to PC. Use speech therapists to assist with interpretation. Communication aids and electronic devices. Accompanied by staff/family during hospital stays. Reduce transitions and create familiar environments. GP as key player.	Paternalistically protecting other residents from grief. Poorly trained staff. High staff turnover. Communication issue. Diagnostic overshadowing. Lack of communication between hospital & community services. Lack of ACP = unnecessary ED admissions. Lack of funding. People with ID 'hidden' by society.
(Moro et al., 2017)	Agency, social and healthcare supports for adults with intellectual disability at the end of life in out-of-home, non-institutional community residences in Western nations: A literature review	Journal of Applied Research in Intellectual Disabilities	USA	Literature review	To summarize the literature on the agency, social and healthcare supports that impact the care of adults with ID at the end of life	Adults with ID/end of life care needs and those caring for them	All health & social care settings	Transitioning needs: home/ residential care/ nursing home/ hospital. Expressing & documenting wishes. Care at home. Information. Help to understand diagnosis & prognosis. Proximity of family accommodated.	Time to build relationships between staff, patient and family. Partnerships between ID and PC. Education.	Lack of staff training. Collusion. Proxy decision making. Reluctance to investigate/ late diagnosis. Under AND over treatment. Transportation barriers and a lack of accessible medical equipment in hospitals: hindering admission for medical care. Poor communication/ negative rapport with patient/ carers.
(Morton-Nance and Schafer, 2012)	End of life care for people with a learning disability	Nursing Standard	England	Face to face interviews	To explore the experiences of LD and district nurses caring for people with a LD at the end of their lives	Community learning disability nurses (n=3), district nurses (n=3), all with experience of providing care for people with ID at EOL.	Community	Being empowered to make choices. Effective and dignified management of symptoms. Physical comfort. Physical and mental pain. Time.	Collaborative working between teams/services. Person-centredness, planning, preparation, outreaching and sharing of information with other HCPs. Training in EOL care and policy. Emotional support for staff and residents.	Staff attitudes: unwillingness to put in extra time, complacency, divide between services, protective/ paternal leading to withholding of info. Specific choices/ decisions not documented creating conflict/ preventing collaborative working. Patient non-compliance with medication. Diagnostic overshadowing. Being reactive rather than proactive. Fragmented communication between HCPs/ patient/ carers, limited sharing of info. Patients' inability to communicate their needs. Inexperience, lack of understanding/ skills/ training. Discomfort when

										discussing death and dying directly with the patient.
(Ng and Li, 2003)	A survey exploring the educational needs of care practitioners in learning disability (LD) settings in relation to death, dying and people with learning disabilities	European Journal of Cancer Care	England	Questionnaires	To explore whether care practitioners have the knowledge and skills to care adequately for dying people with LD in residential settings	25 qualified care practitioners working in residential settings	Residential care homes, 2 NHS Trusts in England.	Psychosocial care, pain and symptom control, use of drugs. Wound care. Cultural awareness. Care after death. Support for family.	Verbal and non-verbal communication skills. Education in EOLC skills. Updating nursing curriculum.	Lack of relevant education and training. Staff understanding of diagnosis and causation of death, particularly non-malignant diseases. Inability to recognise dying. Social care vs medical care - are carers too familiar with social side and lacking clinical skills?
(Northway et al., 2019)	Nursing care at end of life: a UK-based survey of the deaths of people living in care settings for people with intellectual disability	Journal of Research in Nursing	UK	Questionnaire	'What are the levels of support provided by nurses in the last months of life for people with ID?'	38 ID care providers in the UK	Social care residential setting or nursing home for people with ID		Training and education targeted towards community and hospital-based nursing staff: they were shown to have significant involvement in the care of people with ID in last months of life.	
(O'Regan and Drummond, 2008)	Cancer information needs of people withintellectual disability: A review of the literature	European Journal of Oncology Nursing	Ireland	Literature review	A review of the literature with a specific focus on the cancer information needs of people with an ID	Adults with ID and cancer, those caring for them.	All health & social care settings	Cancer information materials that can be accessed and understood by people with an ID. Psychological distress when receiving bad news. Autonomy. Management of side effects: nausea, vomiting, fatigue and pain. Anxiety.	Communication skills/BBN training for ID staff not just oncology. Involvement of family members/carers to aid communication, informed decision making and autonomy. Collaboration/ interdisciplinary approach between oncology, community teams, PC teams and ID services. ID organisations providing access to specialist information and cancer services. Visits to radiotherapy and chemotherapy units prior to treatment. Information leaflets with a wide range of visual content. Education in use of augmentative and alternative communication systems: sign language, picture symbols, eye pointing to support communication and information needs. Hospital policies and protocols.	Poor communication skills. Social taboos/ assumption they will not comprehend resulting in withholding information regarding diagnosis and prognosis.
(O'Sullivan and Harding, 2017)	Transition: the experiences of support workers caring for people with learning disabilities towards the end of life	BMJ Supportive & Palliative Care	England	Focus group	To provide a better understanding of the experience of support workers, as paid carers, caring for adults with LD nearing the end of life in residential settings.	13 residential support workers with direct experience of caring for a person with ID towards the end of life	3 independent service provider settings for people with ID in London		Collaboration with other services. Partnership between ID and SPC services. Support from management within own organisation. Adequate staffing at night. Collaboration/ relationship with family. Early involvement of SPC. Education and training. Emotional support for staff: bereavement.	Denial and a lack of preparedness for seeing residents entering the dying phase of their lives. Lack of access to extra training and support. Standard practice for support workers to be on their own with residents when they were dying. Lack of organisational policy/ guidelines.

(Read and Cartlidge, 2012)	Critical reflections on end-of-life care for people with intellectual disabilities: a single case study approach.	International Journal of Palliative Nursing	England	Case study	To explore the challenges to providing effective end-of-life care for a person with an ID by using critical reflection from a nursing care perspective on an illustrative case study.	36 F with ID and brain tumour	Hospice, England	Day hospice: social contact with others. IPU: symptom assessment or management, respite. Spiritual needs.	Project worker acted as conduit between generic end-of-life care and ID services. Fulfilment of any last wishes to augment a more peaceful death. MDT approach, best interest meeting.	
(Reddall, 2010)	A palliative care resource for professional carers of people with learning disabilities	European Journal of Cancer Care	England	Case study	Use of a case study to help illustrate the value of compiling a resource booklet for professional carers of people with LD.	72 M with ID & prostate Ca	Community, England	Regular contact with GP, medication needs. Loss of appetite. Declining mobility. Urinary incontinence. Pain. Oral thrush. Fear of strangers. A desire to stay at home.	Provision of easy to understand & easily accessible booklet on palliative care for staff in a learning disability care home. Presence of key worker that knows patient for consultations & scans. Interdisciplinary working, shared expertise of ID and SPC. Community team involvement: DNs & Macmillan nurse. MDT reflective session after death.	Carers working in isolation, without access to information/ guidance. Care home manager unaware of how to access SPC team. Poor record keeping. Poor referral info.
(Ronneberg et al., 2015)	Promoting Collaboration Between Hospice and Palliative Care Providers and Adult Day Services for Individuals with Intellectual and Developmental Disabilities	Journal of Death and Dying	USA	Online surveys & focus groups	Not stated.	Surveys: ID service providers (n=103), hospice/PC providers (n=87). Focus groups: adult day service providers (n=10), hospice/PC providers (n=7).	Community, residential home & hospice, USA		Education around recognition of nonverbal symptoms of pain. Well-coordinated services, knowledgeable about one another	Lack of established relationships between ID and hospice services. Few clients receiving dual (hospice and ID) services. Need for training and education for both hospice and ID services. Lack of clearly established and communicated DNR policies, lack of support/ guidance from state government around DNR policies. Misconception that PC patients must always be transferred to hospice for care. Hospice providers limited experience in working with persons with ID. Confusion around funding and regulations. Difficulty having client with extensive medical needs. Staff/family attitudes about death and dying/resistance to hospice philosophy.
(Ryan et al., 2016)	The nature and importance of quality of therapeutic relationships in the delivery of palliative care to people with intellectual disabilities	BMJ Supportive & Palliative Care	Ireland	Focus groups	To describe palliative care delivery to people with ID in a region in Ireland and to assess the population's palliative care needs	91 staff: PC services (n=27), ID services (n=64)	One Health Service Executive area in Ireland	Familiarity, time allowed to build relationships with new HCP. Pain.	Importance of patient-professional relationship: building a therapeutic relationship. Continuity of relationship, knowing the individual, building trust. ID staff familiarity with patient: getting to know them over time. Strengthening interface between PC & ID services.	PC staff unfamiliarity with patients with ID. Over-reliance on carers for communication/ information/ 3 way relationship: prevented PC staff building proper therapeutic relationship. PC staff failure to form authentic relationships with people with ID = poorer quality of care, harder to overcome collusion from family.

(Ryan and McQuillan, 2005)	Palliative care for disadvantaged groups: people with intellectual disabilities	Progress in Palliative Care	Ireland	Literature review	A review of the palliative care needs of people with ID	People with ID and PC needs, those caring for them.	All health & social care settings	Pain. Time to express oneself. Emotional distress. Symptoms expressed as objectively observable signs, rather than spontaneous complaints: e.g. chest pain, dyspnoea, dyspepsia, micturition, hearing and visual loss expressed as irritability, inactivity, loss of appetite and sleep disturbance. Intestinal obstruction in bowel cancer: often undetected due to lack of expressed symptoms & visual signs. Right to information/autonomy. Provision of care on place of choice.	Body map and photographs to communicate symptoms. Use of creative media, art, music, life-story work & audiotapes to overcome communication challenges. Adaptation of standard communication models e.g. BBN where subtlety of warning shot will not be detected. Involvement of carer who knows the individual. Symptom assessment tools for people with ID. High index of suspicion for complications in certain conditions e.g. bowel cancer & obstruction. Effective liaison between ID & PC services. Emotional support for ID staff.	ID patients accessing PC not offered full range of services: e.g. complementary therapy and hospice day-care rarely offered. Cancer better supported than dementia = impact on those with DS. Withholding information, 'a conspiracy of silence.' Varying ability to understand the concept of death: difficult to assess cognitive level & communicate accordingly.
(Sampson et al., 2015)	European palliative care guidelines: how well do they meet the needs of people with impaired cognition?	BMJ Supportive & Palliative Care	Europe	Questionnaires	To review whether national palliative care guidelines in Europe consider pain assessment and management for the increasing numbers of adults with ID	Representatives of the European Pain and Impaired Cognition (PAIC) network	11 European countries			Palliative care guidelines do not universally consider the needs of people with ID. Lack of validated tools or those designed specifically for people with ID.
(Stein, 2008)	Providing Palliative Care to People with Intellectual Disabilities: Services, Staff Knowledge, and Challenges	Journal of Palliative Medicine	USA	Survey	To document the degree to which hospice and palliative care services were provided to New Jersey residents with ID, and the challenges in providing this care	Hospice and PC providers: hospice (n=19), hospitals (n=3). Residential care providers (n=55)	Community, hospice, hospital, New Jersey	Pain. Cognitive and motor deficits. "Human contact is critical." Encouraging autonomy to make decisions.	Strategies and tools for assessing capacity. Staff training. Linking of PC & ID services: educating each other/outreach. Consistent policies & standards.	Lack of staff knowledge and training (within both ID and PC services). Lack of experience with population. Lack of understanding of PC. Communication challenges with patient. Demanding family members. Additional costs (health insurance, medical equipment). Additional staffing. Lack of in-home caregivers. Fear of impact on other residents. Lack of staff support. Caregivers increasingly elderly = lack of able caregiver. Coordinating hospice & ID services. Reluctance by staff/carers to consider DNAR orders. Individuals presumed to lack decision making capacity.
(Sue et al., 2019)	Palliative care for patients with communication and cognitive difficulties	Canadian Family Physician	Canada	Literature review	To explore recent best evidence to address PC needs of people with ID. To help increase the confidence of caregivers and clinicians in providing PC to adults with ID using an easy-to-follow framework.	People with ID and PC needs, those caring for them.	All health & social care settings	Physical pain. Emotional distress. Communication needs. Information needs. Grief, opportunity to express grief nonverbally.	Collaboration between ID & PC services. Early referral to PC allows for longitudinal experience with time to build trust, familiarity, links with services, ACP. Individualised symptom assessment. Involvement of closest caregiver. Versatile symptom assessment tools e.g. DDAT, Abbey. Careful examination of distress patterns, thorough physical examination, and judicious use of diagnostic testing. Communication aids: books, visual tools. Allowing extra time.	**Caregiver:** Lack of understanding or regarding focus of care in advanced life-limiting illness. Ill-equipped for open communication regarding dying and death. Fear of upsetting patient. **HCP:** Communication barriers, over-reliance on carers for communication, assumption of lack of capacity, stress related to lack of experience. Inadequate use of standardised assessment tools. Difficulty distinguishing between physical pain & emotional distress = inappropriate use of analgesics. Overemphasis on role of cognitive ability in QOL = limitation of care options offered, i.e. undervaluing a

										patient's life. Unclear trajectories, unexpected recovery after deterioration = difficult to prognosticate. **Patient:** Difficulty understanding abstract concepts relating to death.
(Tuffrey-Wijne, 2003)	The palliative care needs of people with intellectual disabilities: a literature review	Palliative Medicine	England	Literature review	To answer the question: What are the palliative care needs of people with ID?	People with ID and PC needs, those caring for them.	All health & social care settings	Increase in age-related morbidities. Need for care in the community. Pain. Need to explain likely symptomatic course of an illness.	ID staff supported by primary care staff and palliative care specialists. Involvement of those who know patient well to help interpret individual pain behaviours. Symptom assessment tool for non-verbal communication of pain. Training and education for HCP and carers. Partnership between ID and PC services.	Diagnostic overshadowing. Difficulty obtaining consent, assuming patients lack ability to consent.
(Tuffrey-Wijne et al., 2007a)	End-of-Life and Palliative Care for People with Intellectual Disabilities Who have Cancer or Other Life Limiting Illness: A Review of the Literature and Available Resources	Journal of Applied Research in Intellectual Disabilities	UK & Netherlands	Literature review	To review the literature around the need of people with ID for palliative care	Adults with ID & PC needs	All health & social care settings	Right to know diagnosis and prognosis. Information in accessible format. Pain. Need for social network: friends & family. Familiar environment with familiar people.	Committed and well supported staff. Collaboration between HCPs, ID staff & family. Openness and disclosure. Use of tools/pictures to assess pain. "Skilled observation together with an intimate knowledge of the person." ACP: advance directives. Careful consideration of capacity involving MDT, carers & family. Equipping ID residential services with resources & training to provide PC. Familiar environment with familiar people. Training manuals, protocols, guidelines.	Late presentation, diagnostic overshadowing, difficulty identifying symptoms, resulting in advanced disease with severe symptomatology. Lack of ID staff experience/training in caring for dying. Communication difficulties hindering recognition of pain: overreliance on carers. Overtreatment: reluctance to withdraw futile treatments for fear of litigation. Undertreatment: not giving option of life-prolonging treatment. Understaffing, lack of training, staff anxiety. Lack of evidence base.
(Tuffrey-Wijne et al., 2007b)	Palliative care provision for people with intellectual disabilities: interviews with specialist palliative care professionals in London	Palliative Medicine	England	Interviews	To identify the issues affecting the delivery of services by specialist palliative care professionals to people with ID in London	SPC professionals (n=32). (Only 24 had seen patients with ID within PC).	3 hospices & 3 hospital PC teams in Greater London, representing suburban as well as inner city communities	Personal care needs: washing etc. (independence inhibited by illness). Fear/anxiety, existential distress. Emotional support for family. Community care to avoid change of environment. Mental health problems.	Support for care staff: educational, building confidence. Liaising with ID professionals who know the patient well: particularly helpful with mental capacity and consent. Early referral to PC. Taking time to build relationship/trust = aids examination & assessment. Good background info on individual patient more valuable than formal training. Increase referrals: one learns best through experience. Collaboration between carers, PC & ID services: awareness of each other.	**Social:** Overprotectiveness from family. Poor communication with family/carers. Lack of NH that can meet needs of ID patients. **Emotional and cognitive:** Patient confusion/fear compounding communication barriers, inappropriate assessment of cognitive function. **Assessment:** diagnostic overshadowing, lack of information, examining, non-compliance with medication. **Impact on ward and staff:** grief & stress, need for extra time & staff. **PC staff:** lack of training/ experience, lack of knowledge of ID services. **ID staff**: patients referred late or not at all to PC.

(Tuffrey-Wijne et al., 2008)	Palliative care provision for people with intellectual disabilities: a questionnaire survey of specialist palliative care professionals	Palliative Medicine	England	Postal questionnaire	To gain insight into the current use of PC services by people with ID in London, to identify the prevalence and severity of problems faced by PC professionals, to identify strategies that will facilitate an improvement in access and delivery of PC services to people with ID.	SPC professionals providing PC services for adults (n=543). Of these, 67%, (n=364) had previously supported a patient with ID.	52 SPC services in London: hospice, community & hospital.	Symptom control, Terminal care, Support for carers/ family, Psychological support, Respite care, Day care. Fear. Pain. Emotional distress. Time. Familiarity.	Collaboration between services. Allocating link worker within each service. Formal training. Allowing time. Providing safe and predictable environment with familiar faces. Staff support. Family support.	Late diagnosis. Lack of referral to SPC. Fear of transfer to different setting if referred. Family protection/ fear of PC. Lack of awareness by both SPC and ID services of each other's existence and what each has to offer. Communication difficulties: understanding patient, symptom assessment, consent. Non-compliance with medication/care/ examination. Poor communication with family/carer. Patients' difficulty with comprehending their illness and treatment. Those that spend most time with patient had least training e.g. HCAs. Lack of background information. Difficulty finding suitable long term accommodation when unable to cope at home. Financial concerns.
(Tuffrey-Wijne and McEnhill, 2008)	Communication difficulties and intellectual disability in end-of-life care	International Journal of Palliative Nursing	England	Literature review drawing on 3 research studies conducted by the authors.	To map the communication difficulties experienced by people with ID within a palliative care setting.	People with intellectual disabilities, HCP & carers within a PC setting.	All health & social care settings	Information. Honesty. Time. Difficulty understanding abstract concepts.	Use of communication aids: Objects of reference, sign languages, symbol-based systems. Use of simple, non-euphemistic language, avoid jargon. Allowing extra time for consultations, addressing patient before carer.	**Communication:** Inability of patient to communicate verbally. Inability of HCP to confirm comprehension of diagnosis/treatment. Family collusion.
(Tuffrey-Wijne et al., 2009)	People with learning disabilities who have cancer: an ethnographic study	British Journal of General Practice	England	Ethnographic: participant observation	To explore the experiences and needs of people with LD who have cancer	Adults with ID and a cancer diagnosis (n=13)	Home, residential care home.	Lives defined by dependence on carers. Particularly vulnerable when ill. Anxiety precipitated by not understanding. Fear of cancer. Pain. Continuation of clear/ safe routines, treasured activities, relationships. Loneliness, isolation.	Preparation for appointments, family/ carer present. Explanation of procedures/ treatments in a way that is easy to understand. Familiarity with hospital/ clinic. Maintaining routine. HCP becoming integrated into safe/ trusted environment: a familiar face. Practical and emotional support for residential staff.	Diagnosis dependant on someone other than the patient noticing something is wrong or correctly interpreting behavioural changes: but often unnoticed or misinterpreted. Patient complaints ignored or disbelieved: attributing to 'attention seeking' behaviour. Medical staff guided by opinion of carers, without attempting to check views of patient. Not offered standard treatment options due to assumption that the person would not cope. People with ID unlikely to question treatment decisions. Information giving influenced by; personal opinion of the carer, desire to protect the person from distress and lack of skill and confidence in communicating with them. Family collusion. Acquiescence. HCP lack of experience: communication, fear of opioids, fear of death. Reluctance to ask busy doctors for more input.

(Tuffrey-Wijne, 2013)	A new model for breaking bad news to people with intellectual disabilities	Palliative Medicine	England	A 2-phase qualitative study: (1) focus group meetings, on-line focus groups, interviews; (2) structured feedback.	To develop a model for breaking bad news that meets the needs of people with ID	26 ID professionals & 34 general health professionals with experience of supporting an adult patient with IDs who had a life-limiting illness. (Also 21 people with IDs and 28 family carers but experience of life-limiting illness not stated in study).	Not stated.	People with IDs should be helped as much as possible to understand their situation. Helping someone with IDs understand and cope with bad news is a slow process with knowledge and understanding building gradually over time. Need time and support from the person's network: family & professionals. Emotional support.	Process of disclosing bad news should involve collaboration between those who understand the content of the information (health care professionals) and those who best understand the patient's communication needs (family). Use of a model for breaking bad news to people with ID. Emotional support for staff who may also be affected by bad news: in turn helps them to support the patient.	Family wish to protect the person with ID "I think I'd lie for his own good." Uncertainty about whether bad news should be given. Conflict between family and physician: "the family are not my patient." Conflict between family and ID nurse: barred from visiting. Difficult to assess how much someone can truly understand: PC consultant found they had not understood when it initially appeared that they had.
(Tuffrey-Wijne et al., 2016)	Defining consensus norms for palliative care of people with intellectual disabilities in Europe, using Delphi methods: A White Paper from the European Association of Palliative Care	Palliative Medicine	Europe	Delphi study using MM.	To define consensus norms for palliative care of people with ID in Europe	Professionals with expertise in PC, ID or both (n=80).	15 European countries, all health & social care settings.	Communication needs. Holistic approach: physical, emotional, social and spiritual needs. Counselling, support in maintaining social links with friends. Pain. Comorbidities. A right to life and a right to recognition of the value of their lives. Complicated grief.	ID services refer to PC when appropriate, PC services make necessary adjustments. HCP to recognise communication needs, strive to understand and to seek necessary training, support patient communication using methods that suit them, encouragement involvement in EOL decision making, ACP. Skills to recognise illness, deterioration and dying. Individual, person-centred care plans. Recognition that total needs exist as they do for patients without ID: holistic approach. Awareness that symptoms are expressed differently: collaboration with those who know the person well. Awareness of legal frameworks around capacity & consent. Involvement of family/carers/friends. Collaboration between services. Emotional support for family/carers. Education and training: for staff AND death education for patients. Prioritisation amongst policy makers and managers.	Diagnostic overshadowing.
(Tuffrey-Wijne et al., 2017)	Communicating about death and dying: Developing training for staff working in services for people with intellectual disabilities	Journal of Applied Research in Intellectual Disabilities	England	Stage 1: Semi-structured interviews. Stage 2: Development & evaluation of training course - feedback forms and questionnaires.	To assess staff training needs and to develop, trial and evaluate a training course on communicating about death and dying	Stage 1: 20 staff working in ID residential or supported living services (13 had supported people with ID who had died in the past 6 months). Stage 2: 114 interprofessional delegates, 108 completed feedback forms and questionnaires + 24 follow-up questionnaires at 3 months.	8 different ID residential or supported living services in London, UK		Organisational culture: junior staff felt more comfortable talking about loss, death and dying in settings where managers talked with staff and clients about death, providing positive role modelling. Staff training to improve the ability to talk about death and dying, not only with people with ID but also with each other. World Café approach: helping course delegates to talk about death and dying and "role-modelling" ways in which they could help their teams do the same. Involving people with ID by	UK ID services: workforce, especially junior care staff, is largely untrained - often learn on the job. Staff frightened and unprepared for dealing with issues of death and dying, avoidance of death-related conversations, concerned that communicating about death might cause distress, partly due to their own lack of skill. Not knowing how to break bad news. Avoidance of death-related communication had roots in organizational culture. Tendency among staff to "keep things positive." Lack of preparation and training for the job of care worker was striking. Lack of

									telling their own stories as part of staff training. Targeting training towards managers.	guidance for staff in death-related communication; staff communication was influenced by personal beliefs or opinions. Emotional support for staff to help them better cope with death and dying.
(Tuffrey-Wijne and Davidson, 2018)	Excellence in palliative and end-of-life care provision for people with intellectual disability	International Journal of Palliative Nursing	UK	Thematic content analysis	To identify the key characteristics of practice initiatives and case reports that have won a UK award for the outstanding provision of end-of-life care for people with ID (2008–2018).	People, projects or teams who were award-winners or highly commended (n=25).	Nursing/residential home, hospice, community, UK		**Individual and organisational commitment:** Enthusiastic individuals/leaders going beyond the call of duty. Adequate funding and policies. **Working together in collaboration:** between LD and PC, with patients, carers, families. Regular meetings. Mutual learning. Availability of required professionals, 24/7 care, continuity of care. **The person's story is at the heart of care:** Highly individualised care, creative & flexible, familiarity with patient, maintaining care in home environment, involving & supporting family. **Developing tools and staff training:** Inter-professional, regular, compulsory, conferences, use of GSF, tools and pathways, early referrals, ACP, adapting from mainstream.	Lack of national policies and adequate funding = postcode lottery, good initiatives not sustained when staff leave. "Good palliative care for people with ID should not be dependent on the fortunate presence of committed professionals with a passion for this area of care, or on being within the catchment area of one of these inspirational projects and services. Nor should it be up to a small charitable organisation like the PCPLD Network..."
(Vrijmoeth et al., 2016a)	Physician-Reported Symptoms and Interventions in People with Intellectual Disabilities Approaching End of Life	Journal of Palliative Medicine	Netherlands	Online retrospective survey	To determine the prevalence rates of physician-reported symptoms at the moment they recognise patient's death in the foreseeable future.	ID physicians who had provided PC to a deceased patient with ID (n=81).	All health care settings, Netherlands	Physical/symptom needs: fatigue, drowsiness, decreased appetite, shortness of breath, pain, anxiety, depressed mood, nausea, constipation, delirium. Medical needs: sedation, wound care, antibiotics, artificial nutrition & hydration, surgery, chemo or radiotherapy, blood transfusion.	MDT approach to symptom control, use of proxies who know patient well, use of symptom assessment tools.	
(Vrijmoeth et al., 2016b)	Physicians' recognition of death in the foreseeable future in patients with intellectual disabilities	Journal of Intellectual Disability Research	Netherlands	Online retrospective survey	To explore when and based on which information sources and signals physicians recognised that a patient with ID would die in the foreseeable future	ID physicians (n=81) & GPs (n=16) who had provided PC to a deceased patient with ID.	All health care settings, Netherlands		Close attention to changes in characteristic behaviour or mood. Gathering information/ collaborating with caregivers & family. Use of tools.	Physician delayed recognition of dying phase in people with ID & delayed discussion of PC until time when death is foreseeable. Diversity in signals that lead to recognition of death. Patient inability to communicate.

(Vrijmoeth et al., 2018)	Development and applicability of a tool for identification of people with intellectual disabilities in need of palliative care (PALLI)	Journal of Applied Research in Intellectual Disabilities	Netherlands	Mixed-methods: online retrospective survey, interviews, focus groups, prospective pilot	To describe the development of PALLI and to explore its applicability as reported by healthcare professionals	**Survey:** GPs (n=16), ID-physicians (n=81). **Interviews:** ID-physicians (n=10), GPs (n=6), DCPs (14). **Focus groups:** ID-physicians (n=11), GPs (n=5), PC nurses for people with ID nurses (n=10), DCPs (n=14). **Pilot:** adults with ID, likely to be in last year of life (n=185).	All health care settings, Netherlands		Use of a tool to identify and assess people with ID who are in need of PC. Includes signals relevant and characteristic to people with ID. Can be completed by physician or carer proxy.	
(Wagemans et al., 2013)	End-of-life decisions for people with intellectual disabilities, an interview study with patient representatives	Palliative Medicine	Netherlands	Qualitative interviews	To clarify the process of end-of-life decision making for people with intellectual disabilities from the perspective of patient representatives.	Family or legal representative of person with ID that had died (n=16)	All health care settings, Netherlands		Doctors closely involved in decision making process, give time to think and deliberate. Building relationships with family.	Over-reliance on family to make complex medical & ethical decisions with limited guidance from professionals. Failure to involve people with IDs themselves in decision making process.
(Wark et al., 2017)	Challenges in providing end-of-life care for people with intellectual disability: Health services access	Journal of Applied Research in Intellectual Disabilities	Australia	Focus group interviews	To explore staff perceptions of the strengths and barriers associated with health service access for people with ID at the end of life	Paid disability support staff who had provided end-of-life support to an individual with an ID (n=35).	4 rural & 2 metropolitan locations, NSW & Queensland		Dr available 24/7. Dr comfortable in supporting people with ID. Community-based health services.	Isolation of staff in rural locations: coping with very complex medical situations with limited resources or advice from health services. Rural patients required to travel long distances to access services. Shortage of rural GPs. Drs refusal to take on patients with ID during the end-of-life: lack of time. Dealing with 'the 'immediate' but no continuity. Diagnostic overshadowing & failure to investigate new health issues. Attitude that using limited resources on people with ID is a waste of money. Drs not prioritizing medical assistance for health issues separate to the existing life-ending condition. Lack of training amongst community & hospital HCPs. Being put in the "too-hard basket." Lack of funding to support additional healthcare needs at EOL. Lack of staff, additional hours required, other residents overlooked to meet the healthcare demands of the dying. Staff fear of caring for the dying: preference to transfer to hospital/NH. Staff stress, recruitment & retention.
(Welch and Moreno-Leguizamon, 2016)	Literature review of best health and social care practices for individuals with intellectual disabilities encountering the end of life	Nursing and Palliative Care	England	Literature review	To identity what were care best practices for individuals with ID encountering the end of life.	Individuals with ID at end of life and those caring for them	All health & social care settings	Culturally competent care. Hydration/nutrition. Pain. Grief & loss. Information. Autonomy.	Training courses, training manuals. Management support. Working strategically & collaboratively with other professionals, within & between organisations. Collaboration with family. Use of communication tools, non-verbal cues, adjusting language. Continuity. Building relationships. Respecting	Lack of policies and procedures governing end-of-life care decision making processes. EOL care provided by mainstream services that are not developed to meet requirements of people with ID. Lack of staff knowledge/experience, lack of time. Staff stress, bereavement. Organisational policy & practice preventing individually-styled approached to communication.

									autonomy. Integrating views of service users into models of care. Time/patience/flexibility. Evidence-based care.	Communication difficulties with patient: ascertaining information requirements, wishes, symptoms.

Abbreviations:
ACP=advance care planning, BBN=breaking bad news, Ca=cancer, CLDT=community learning disability team, CP=cerebral palsy, DCPs=daily care professionals, DNR=do not resuscitate, DNs=district nurses, ED=emergency department, EOL=end of life, F=female, GSF=gold standards framework, H@H=hospice at home, HCA=health care assistants, HCP=health care professionals, ID=intellectual disability, info=information, M=male, MDT=multidisciplinary team, MM=mixed methods, NH=nursing home, NHL=Non-Hodgkin Lymphoma, PC=palliative care, PPD=preferred place of death, Pts=patients, SPC=specialist palliative care

Appendix 3: Hawker et al's critical appraisal tool

---

1. Abstract and title: Did they provide a clear description of the study?
   - Good: Structured abstract with full information and clear title.
   - Fair: Abstract with most of the information.
   - Poor: Inadequate abstract.
   - Very Poor: No abstract.
2. Introduction and aims: Was there a good background and clear statement of the aims of the research?
   - Good: Full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge.
     Clear statement of aim AND objectives including research questions.
   - Fair: Some background and literature review.
     Research questions outlined.
   - Poor: Some background but no aim/objectives/questions OR Aims/objectives but inadequate background.
   - Very Poor: No mention of aims/objectives.
     No background or literature review.
3. Method and data: Is the method appropriate and clearly explained?
   - Good: Method is appropriate and described clearly (e.g., questionnaires included).
     Clear details of the data collection and recording.
   - Fair: Method appropriate, description could be better.
     Data described.
   - Poor: Questionable whether method is appropriate.
     Method described inadequately.
     Little description of data.
   - Very Poor: No mention of method, AND/OR
     Method inappropriate, AND/OR No details of data.
4. Sampling: Was the sampling strategy appropriate to address the aims?
   - Good: Details (age/gender/race/context) of who was studied and how they were recruited.
     Why this group was targeted.
     The sample size was justified for the study.
     Response rates shown and explained.
   - Fair: Sample size justified.
     Most information given, but some missing.
   - Poor: Sampling mentioned but few descriptive details.
   - Very Poor: No details of sample.
5. Data analysis: Was the description of the data analysis sufficiently rigorous?
   - Good: Clear description of how analysis was done.
     Qualitative studies: Description of how themes derived/respondent validation or triangulation.
     Quantitative studies: Reasons for tests selected hypothesis driven/numbers add up/statistical significance discussed.
   - Fair: Qualitative: Descriptive discussion of analysis.

Quantitative.

Poor	Minimal details about analysis.
Very Poor	No discussion of analysis.

6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?

Good	Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed. Bias: Researcher was reflexive and/or aware of own bias.
Fair	Lip service was paid to above (i.e., these issues were acknowledged).
Poor	Brief mention of issues.
Very Poor	No mention of issues.

7. Results: Is there a clear statement of the findings?

Good	Findings explicit, easy to understand, and in logical progression. Tables, if present, are explained in text. Results relate directly to aims. Sufficient data are presented to support findings.
Fair	Findings mentioned but more explanation could be given. Data presented relate directly to results.
Poor	Findings presented haphazardly, not explained, and do not progress logically from results.
Very Poor	Findings not mentioned or do not relate to aims.

8. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population?

Good	Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).
Fair	Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.
Poor	Minimal description of context/setting.
Very Poor	No description of context/setting.

9. Implications and usefulness: How important are these findings to policy and practice?

Good	Contributes something new and/or different in terms of understanding/insight or perspective. Suggests ideas for further research. Suggests implications for policy and/or practice.
Fair	Two of the above (state what is missing in comments).
Poor	Only one of the above.
Very Poor	None of the above.

Appendix 4: Grading of quality

Item score:
Good = 4, Fair = 3, Poor = 2, Very Poor = 1

Total score:
18 or less = poor
19 to 27 = moderate
> 27 = good

Hawker's 9 item checklist:	1. Abstract and title: Did they provide a clear description of the study?	2. Introduction and aims: Was there a good background and clear statement of the aims of the research?	3. Method and data: Is the method appropriate and clearly explained?	4. Sampling: Was the sampling strategy appropriate to address the aims?	5. Data analysis: Was the description of the data analysis sufficiently rigorous?	6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?	7. Results: Is there a clear statement of the findings?	8. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population?	9. Implications and usefulness: How important are these findings to policy and practice?	**Total**	**Overall grade**
Bailey et al. 2016	3	4	4	2	4	3	4	3	3	**30**	**Good**
Bekkema et al. 2014a	3	4	3	2	4	2	3	3	3	**27**	**Moderate**
Bekkema et al. 2014b	4	3	4	3	4	3	4	3	3	**31**	**Good**
Botsford 2004	3	3	3	2	2	2	3	2	3	**23**	**Moderate**
Brown et al. 2003	2	2	2	3	2	2	3	3	2	**21**	**Moderate**
Cartlidge 2010	4	4	4	3	3	4	3	3	3	**31**	**Good**
Codling et al 2014	3	4	3	3	3	1	3	3	3	**26**	**Moderate**
Cross et al. 2012	3	3	2	2	2	1	3	3	3	**22**	**Moderate**
Dunkley & Sales 2014	3	3	4	4	3	3	4	4	4	**32**	**Good**
Flynn et al 2015	3	3	4	3	3	3	3	2	2	**26**	**Moderate**
Forrester-Jones et al. 2017	4	3	4	3	4	4	3	3	3	**31**	**Good**
Friedman et al 2012	3	3	3	3	3	3	3	4	3	**28**	**Good**
Gilbert et al. 2007	1	1	3	2	2	2	3	2	2	**18**	**Poor**
Grindrod & Rumbold 2017	4	3	3	3	4	2	4	3	4	**30**	**Good**
Hunt et al 2019	4	4	4	4	4	1	4	3	3	**31**	**Good**
Kim & Gray 2018	4	3	3	3	4	4	4	2	2	**29**	**Good**
Kinley et al 2018	4	3	3	2	2	1	3	2	3	**23**	**Moderate**
Lindop & Read 2000	3	4	3	3	3	1	2	2	3	**24**	**Moderate**

Marriott et al 2013	4	3	3	2	1	1	2	1	2	**19**	**Moderate**
McKechnie 2006	3	2	1	1	1	1	2	2	2	**15**	**Poor**
McLaughlin et al. 2014	4	3	4	3	4	3	3	3	3	**30**	**Good**
McNamara et al. 2019	4	3	3	3	3	3	4	3	3	**29**	**Good**
Moro et al. 2017	4	4	3	4	3	2	3	3	3	**29**	**Good**
Morton-Nance & Schafer 2012	4	4	4	2	3	3	3	2	2	**27**	**Moderate**
Ng & Li 2003	3	3	3	3	3	3	3	2	3	**26**	**Moderate**
Northway et al. 2019	4	3	3	3	3	2	3	2	3	**26**	**Moderate**
O'Regan & Drummond 2008	3	2	2	2	2	2	3	3	3	**22**	**Moderate**
O'Sullivan & Harding 2017	4	3	3	2	4	3	3	2	3	**27**	**Moderate**
Read & Cartlidge 2012	4	3	3	2	2	4	3	2	2	**25**	**Moderate**
Reddall 2010	3	3	2	2	2	1	3	2	2	**20**	**Moderate**
Ronneberg et al 2015	2	1	2	2	2	1	3	2	2	**17**	**Poor**
Ryan et al 2016	4	3	3	2	3	1	3	2	3	**24**	**Moderate**
Ryan & McQuillan 2005	3	2	1	1	1	1	3	2	2	**16**	**Poor**
Sampson et al. 2015	4	4	3	3	3	1	3	3	3	**27**	**Moderate**
Stein 2008	3	2	3	2	2	1	3	2	3	**21**	**Moderate**
Sue et al 2019	3	2	2	3	2	1	3	3	3	**22**	**Moderate**
Tuffrey-Wijne 2003	4	3	3	3	3	2	3	3	3	**27**	**Moderate**
Tuffrey-Wijne et al. 2007 (a)	4	3	4	3	3	3	3	3	3	**29**	**Good**
Tuffrey-Wijne et al. 2007 (b)	4	3	3	2	3	3	3	2	3	**26**	**Moderate**
Tuffrey-Wijne et al. 2008	4	3	3	3	3	3	3	3	3	**28**	**Good**
Tuffrey-Wijne & McEnhill 2008	4	3	2	2	1	1	3	2	3	**21**	**Moderate**
Tuffrey-Wijne et al. 2009	4	3	4	4	4	2	3	3	3	**30**	**Good**
Tuffrey-Wijne 2013	4	4	3	3	4	4	3	3	3	**31**	**Good**

Tuffrey-Wijne et al. 2016	4	3	4	4	3	3	4	3	4	**32**	**Good**
Tuffrey-Wijne et al 2017	4	4	3	2	3	3	3	3	3	**28**	**Good**
Tuffrey-Wijne & Davidson 2018	4	3	4	4	3	3	4	2	3	**30**	**Good**
Vrijmoeth et al. 2016 (a)	4	3	4	3	4	1	4	3	3	**29**	**Good**
Vrijmoeth et al 2016 (b)	4	3	3	3	3	3	3	2	3	**27**	**Moderate**
Vrijmoeth et al 2018	4	3	4	3	3	3	3	2	3	**28**	**Good**
Wagemans et al. 2013	4	3	4	3	4	2	3	2	3	**28**	**Good**
Wark et al. 2017	4	2	3	2	3	3	3	2	3	**25**	**Moderate**
Welch & Moreno-Leguizamon 2016	3	3	4	4	3	3	3	3	3	**29**	**Good**